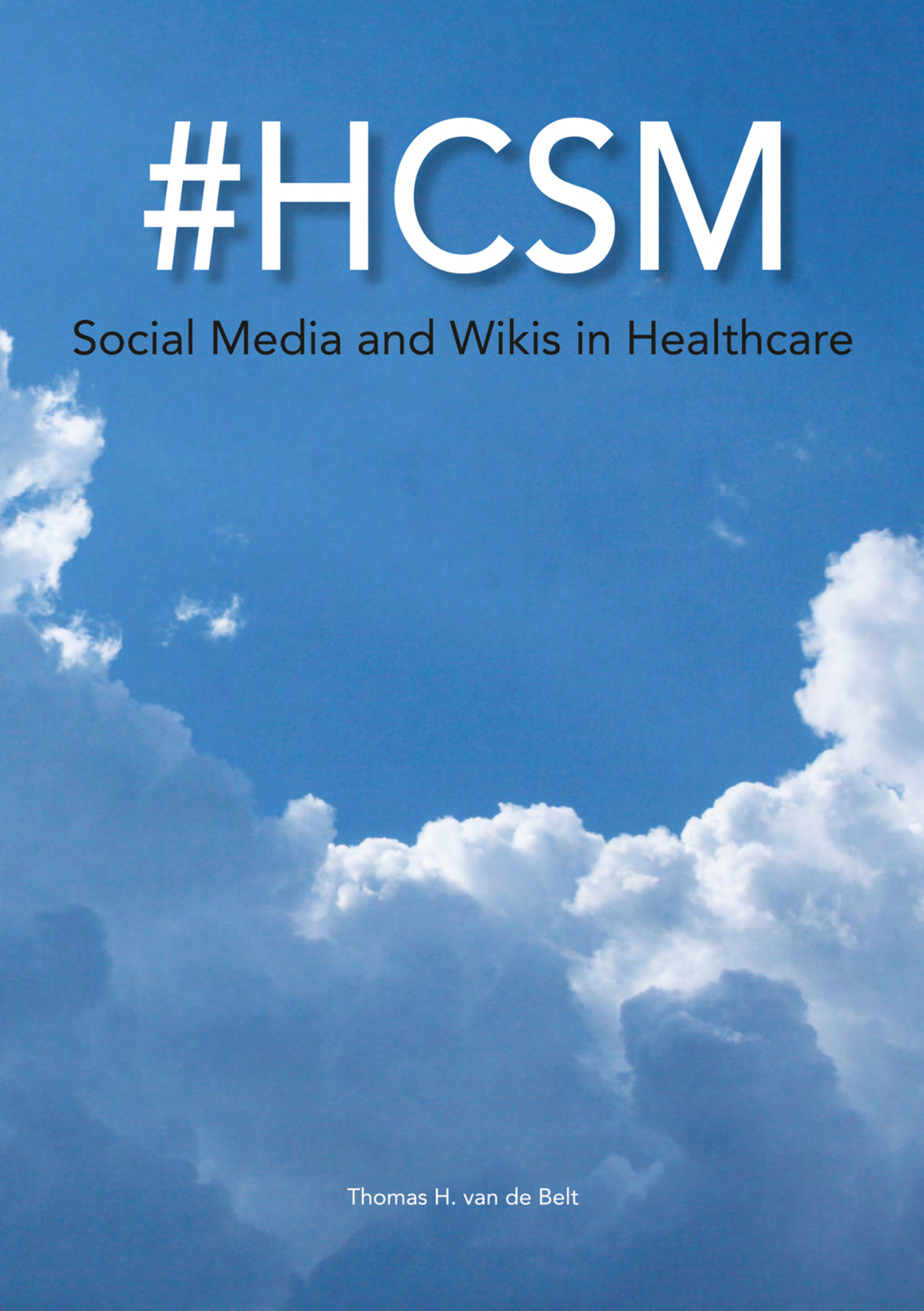
#HCSM
Social Media and Wikis in Healthcare
Thomas H. van de Belt

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Social Media and Wikis in Healthcare

For reasons of consistency within this thesis, some terms have been standardized throughout the text. As a consequence the text may differ in this respect from the articles that have been published.

The studies presented in this thesis have been performed at the Nijmegen Centre of Evidence Based Practice (NCEBP), one of the approved research institutes of the Radboud University Medical Centre.

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#HCSM
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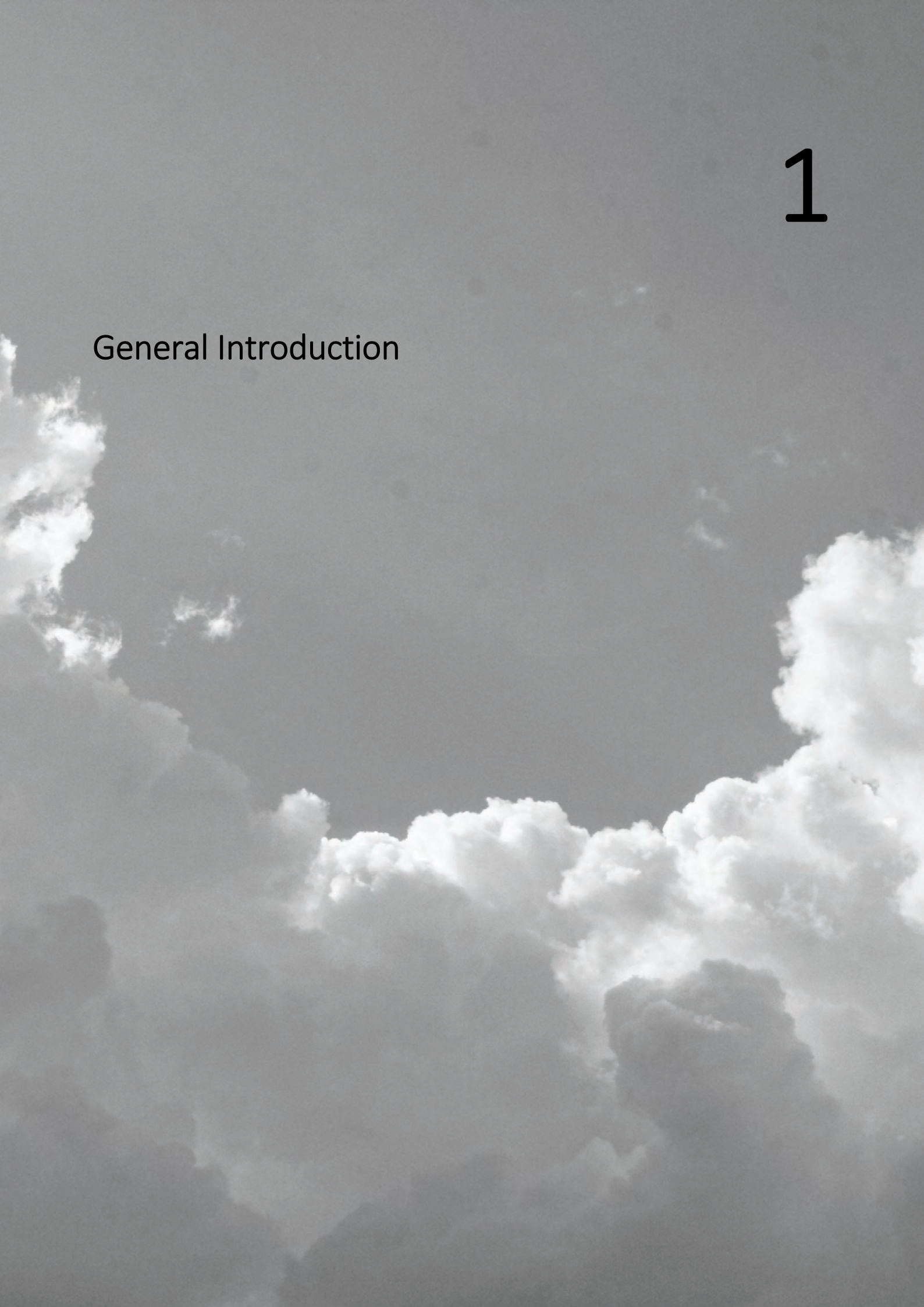


1

General Introduction

Last decade, Internet access and use have increased enormously. A vast majority of people in the western world uses the Internet on a daily basis, for an abundance of purposes. It affects their work, social lives and leisure time [1,2]. Finding job vacancies, products or even a potential partner is easy. Internet also allows social virtualization [3], which means that people connect online with their friends, using social media like Twitter, YouTube and Facebook. As a result, the online world has become an integral part of our society and is rapidly changing the way people are connected and interact with each other. Where the baby boomers (born between World War 2 and 1960) and "generation X" (born between 1960 and 1980) [4] were mostly connected through real-life groups like church, colleagues and a sports team, nowadays' people are increasingly enrolled in many, often online social networks. An 'offline to online trend' is recognized [5].

Using this full potential of Internet and particularly social media, individuals acquire the ability to perform things that were difficult or impossible in the past. An example is the recent revolutions in the Middle East. Civilians started using social media to communicate and to share information. It enabled them to unite and arrange effective protests. In the end, they sometimes successfully revolted against their leaders. Although revolutions have happened without social media in the past, it is believed that it played a crucial role [6-8].

Supported by social media, consumers also obtained a new role in the public and commercial sector. They want business organizations to take their opinion very seriously [9]. The new role of consumers has tremendous consequences for the business world and business models [10]. Consumers not only buy and compare products online, but they also discuss product features and brands with other consumers or friends. For example, an individual that is looking for a hotel on booking.com can make use of other people's experiences with, and recommendations about hotels. Sometimes even specified for his age, gender and marital status. Not surprisingly, it is unlikely that this person will select a hotel if an earlier visitor has shared negative experiences (e.g. dirty rooms, poor Wi-Fi connection) about it. As a result, hotel owners should listen to their guests and deal with problems immediately, particularly because customers' experiences can spread very quickly. If they don't, they risk their guests staying away. Wiederhold et al. described that a shift of power has occurred [11]. The new role of consumers can even affect a business company's sales, reputation and survival [10]. Consequently, entrepreneurs need to find new business models as the models that have been successful for decades have become less appropriate.

Technological advances

Currently, we are in the middle of a period in which our economy is mainly based on information computerization, which is also known as the information age [12]. It is the result of a digital revolution, sometimes described as the third Industrial Revolution [13]. Especially the Internet has altered the way we exchange information. Until ten years ago, the Internet was primarily a one-way 'download environment' in which users were able to visit webpages and to download content like written text, audio and video. Supported by technological developments, it evolved to an

environment with interactive components. This modified version of the web in which participation is stimulated and users are empowered is often described as "Web 2.0" [14-16]. More specifically, it is defined as "a set of economic, social, and technology trends that collectively form the basis for the next generation of the Internet, a more mature, distinctive medium characterized by user participation, openness, and network effects" [17]. One of the key features is user-generated content, which means that Internet users have become contributors [15,18]. They can quickly share information via social media channels e.g. posting a photo on Flickr, a video on YouTube or a story on a blog. A second feature of Web 2.0 is the possibility to efficiently find content. Although user-generated content has led to an almost unimaginable abundance of online data, finding relevant information is still relatively easy. Smart search engines like Google support users to find the most relevant sources (including social media resources) quickly. Since most content is shared on social networks, users simply have to find those groups to get access. Third and last, people can use the Internet independently from time and place [19,20]. They no longer need a desktop computer or a laptop but can use tablet PCs, smartphones or smart televisions to connect to the web. Since Social Media are one of the main manifestations of Web 2.0, its features have been studied separately. Kaplan et al. (2010) describe social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content" [18]. In this thesis, we define social media following the classification scheme presented by Hoffman and Novak, 2012, who recognize that social media engage people and identify four main social media features: (1) Connect (e.g. with peers), (2) Create (e.g. creating blogposts, tweets), (3) Consume (e.g. watch a video) and (4) Control (e.g. rate contributions) [2].

Health 2.0

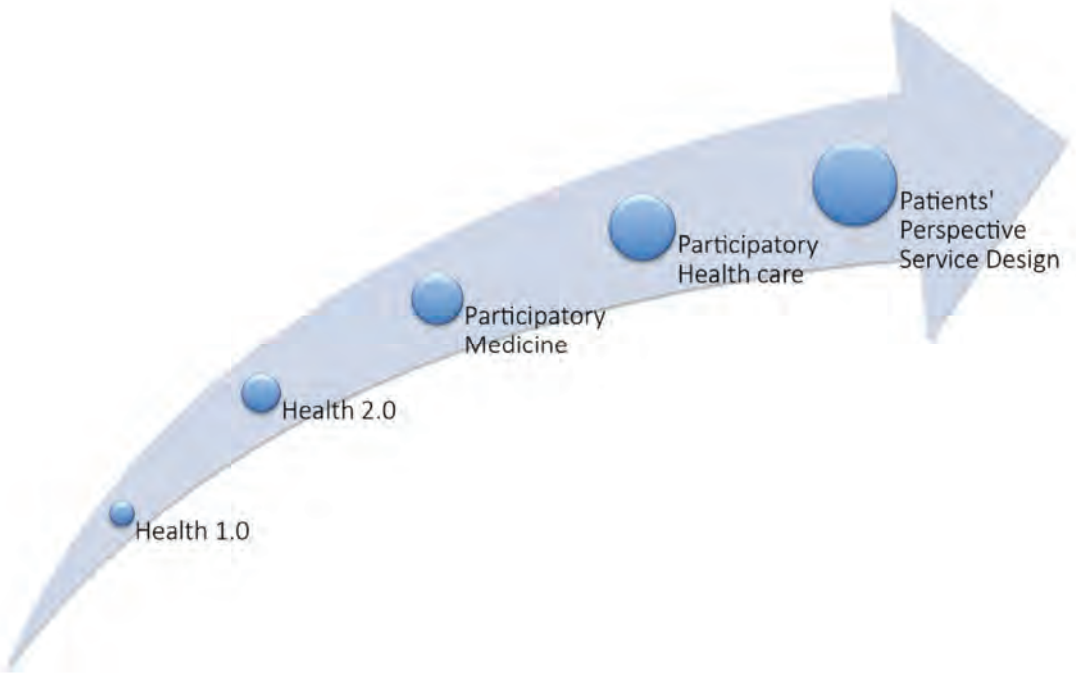
As Internet and social media facilitate change of our entire society, they also affect health care. Different terminology has been used. In 2006, the term Web 2.0 was introduced to health care by Giustini (2006) [21]. He described that the interactive component of Web 2.0 could affect health care in a positive way. For example, blogs and collaborative writing tools like wikis could facilitate participation and efficient dissemination of knowledge, and other tools like RSS allow health care professionals to retrieve knowledge efficiently. Later on, the terms "Health 2.0" and "Medicine 2.0" appeared, as a synonym for the use of Web 2.0 technology in health care [22]. However, the two terms may entail more than simply "Health + Web 2.0" [23]. Furthermore, no uniform definition of Health and Medicine 2.0 exists [24], and debate about the definition is ongoing [25-27].

Social media and health care

Although the effects of social media on health care have not yet been studied intensively and there is no "gold standard" evidence [3], it is expected that the collaborative nature of Web 2.0 technology and social media can lead to quality improvements in health care, via several ways. First, it improves the way people communicate and stimulates direct communication between

patients and professionals [28,29]. Second, it allows patients to become better informed since new technologies allow quick access to information [21,30]. As a result, patients are able to make more appropriate decisions and have more control over their care [29,31,32], which allows them to become equal partners of health care professionals [30]. As patients demand more responsibility regarding their own care pathway, it is expected that Health 2.0 will evolve into participatory medicine and health care and a patients' perspective service design [33]. Service design is a term that originated in the business world and is used to describe the development of services to improve the quality or interaction between providers and consumers, by respecting the consumers' needs. This assures that the service is user-friendly, competitive and relevant for the user [34]. Service designs have already been applied to health care [35]. The migration to a patients' perspective service design is shown in Figure 1.

Figure 1. Migration of Health 1.0 into Patients' Perspective Service Design



Despite the expected beneficial effects that Web 2.0 technologies and social media may offer to health care, it is difficult to predict in which way this will happen and what the consequences will be [30]. As many technologies and tools exist, it is unclear which ones are likely to stay and which ones will disappear. Furthermore, it is difficult to predict how fast new technologies will affect health care e.g. communication between patients and professionals using new communication tools. Furthermore, little is known about the downsides of Health 2.0. For example, privacy issues are at stake when difficulties to differentiate public postings and private postings occur [36].

Examples of how patients use the internet and social media

Patients use the Internet and social media for three main purposes. First, they can use it to find relevant information about health, diseases, treatment options or ratings of health care providers quickly. Second, they can share their story online using social media like Blogs, YouTube or health-related social media like Carepages [37]. Third, patients can use the Internet and social media to connect to other people e.g. peer patients, family, friends and health care providers. This can help them to find support [36]. An example of a patient sharing his story online is Maarten Fitzgerald. After he was diagnosed with cancer in 2008, he decided to share his story on his blog to inform everybody about his situation [38]. He shared CT-scans, lab results and visiting schedules. The blog even helped him to get connected with doctors from other countries that evaluated his scans. One of the best examples of a patient network is the US-based PatientsLikeMe, with virtual communities for more than 1000 conditions [39]. In these (sub)communities patients can find support, health related information, share experiences and start discussions about problems they experience.

Examples of how health care providers use the internet and social media

Health care providers can use the Internet and social media for similar purposes as patients. First, it allows them to find information about treatment protocols, techniques or dosage of medication quickly. Popular sources are Facebook, YouTube and Wikipedia [40]. Second, health care providers can share their stories online on weblogs or in online videos e.g. to inform their patients about procedures or discuss rare cases with colleagues. Health care providers also connect using professional online communities. An example of such a community is Sermo, with over 125,000 members (all physicians) worldwide [41]. Sermo consists of 68 specialties, and allows physicians to consult colleagues to obtain and share information. Due to new tools like tablet PCs, Sermo can even be used literally from the bedside. Although health care providers are increasingly aware of new tools, they state that appropriate training is needed [42].

How different stakeholders collaborate using Internet and social media

Furthermore, there are multiple-stakeholder communities e.g. communities that allow patients and professionals to collaborate [29,43]. An example is MijnZorgnet, a Dutch non-profit organization that allows anyone (patient, professional or health care organization) to start a community [44]. Presently, 578 groups for several diseases exist within MijnZorgnet. The largest community has over 2,000 patients and is a community on infertility care. Professionals from one clinic created the community, and all patients are invited to participate. There is a forum to ask and discuss questions and information is shared. Patients are invited to answer their peer patients' questions. Furthermore, patients can start personal communities, and they can invite family members and health care providers (GP, specialist) to join his/her community.

Aims

It is clear that the Internet and especially social media can affect health care and we hypothesize that they will further influence health care in the future. Although positive effects like quality improvements are expected, several questions remain unanswered. This thesis aims to provide an answer to some of those questions by giving insight in the different terminology and the different types of social media that are used and how this process develops over time. Moreover, it gives insight into the feasibility of using social media in health care, and the opportunities and challenges that exist. Therefore, this thesis is a critical step in the development of this new research field. It is divided into two parts. Part one focuses on social media and health care in general. Part two zooms in on two specific examples of social media: collaborative writing applications and forums, both examples of asynchronous communication.

Outline

Part 1. Health care and social media in general

1. Is it possible to define Health 2.0 and Medicine 2.0? (Chapter 2)
2. To which extent are social media being used in health care? (Chapter 3)
3. In which way does the general population use the Internet and Social media to find health-related information and what are the preferences of the general population regarding online communication with health care providers? (Chapter 4)

Part 2. Health care and social media: two examples of asynchronous communication

4. What are online collaborative writing applications and what are positive and negative effects, and barriers and facilitators of using online collaborative writing applications in health care? (Chapter 5 and 6)
5. To which extent is the use of collaborative writing applications feasible to stimulate patient participation and collaboration with health care providers? (Chapter 7)
6. How can online forums be used to improve patient information? (Chapter 8)

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2

Definition of Health 2.0 and Medicine 2.0: A Systematic Review

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Sivera AA Berben
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Journal of Medical Internet Research 2010;12(2):e18.
www.jmir.org/2010/2/e18

Abstract

Background: During the last decade, the Internet has become increasingly popular and is now an important part of our daily life. When new "Web 2.0" technologies are used in health care, the terms "Health 2.0" or "Medicine 2.0" may be used.

Objective: The objective was to identify unique definitions of Health 2.0/Medicine 2.0 and recurrent topics within the definitions.

Methods: A systematic literature review of electronic databases (PubMed, Scopus, CINAHL) and gray literature on the Internet using the search engines Google, Bing, and Yahoo was performed to find unique definitions of Health 2.0/Medicine 2.0. We assessed all literature, extracted unique definitions, and selected recurrent topics by using the constant comparison method.

Results: We found a total of 1937 articles, 533 in scientific databases and 1404 in the gray literature. We selected 46 unique definitions for further analysis and identified 7 main topics.

Conclusions: Health 2.0/Medicine 2.0 are still developing areas. Many articles concerning this subject were found, primarily on the Internet. However, there is still no general consensus regarding the definition of Health 2.0/Medicine 2.0. We hope that this study will contribute to building the concept of Health 2.0/Medicine 2.0 and facilitate discussion and further research.

Introduction

During the last decade, the Internet has become increasingly popular and now forms an important part of our daily life [1]. In the Netherlands, the Internet is even more popular than traditional media like television, radio, and newspapers [2]. Furthermore, the impact of the Internet and other technological developments on health care is expected to increase [3,4]. Patients are using search engines like Google and Bing to find health related information. In Google, five percent of all searches are health related [5]. Patients can express their feelings on weblogs and online forums [3], and patients and professionals can use the Internet to improve communication and the sharing of information on websites such as Cure together [6] and the Dutch website, Artsennet [7] for medical professionals. The use of Internet or Web technology in health care is called eHealth [1,8].

In 2004 the term "Web 2.0" was introduced. O'Reilly defined Web 2.0 as "a set of economic, social, and technology trends that collectively form the basis for the next generation of the Internet, a more mature, distinctive medium characterized by user participation, openness, and network effects" [9]. Although there are different definitions, most have several aspects in common. Hansen defined Web 2.0 as "a term which refers to improved communication and collaboration between people via social networking" [10]. According to both definitions, the main difference between Web 1.0 (the first generation of the Internet) and Web 2.0 is interaction [11]. Web 1.0 was mostly unidirectional, whereas Web 2.0 allows the user to add information or content to the Web, thus creating interaction. This is why the amount of "user-generated content" has increased enormously [12]. Practical examples of user-generated content are online communities where users can participate and share content. Examples are YouTube, Flickr, Facebook, and microblogging such as Twitter. Twitter, for example, improves communication and the sharing of information among health care professionals [13].

According to some critics, Web 2.0 is not a new generation of the Internet because it is still based on old technologies such as HTML, the predominant markup language. Therefore, the term Web 2.0 simply describes renewal or evolution of these older technologies or of the Internet itself [14,15]. Nonetheless, the term Web 2.0 seems to be widely used and accepted. The search engine Google recently found over 85,000,000 results for the search string "Web 2.0 or Web2.0".

When Web 2.0 technologies are applied in health care, the term Health 2.0 may be used [16,17]. Other authors use the term Medicine 2.0, which combines medicine and Web 2.0 [18]. There are many examples of Health 2.0/Medicine 2.0, such as the websites PatientsLikeMe [19] and Hello Health [20]. Recently, the Dutch minister of health awarded a grant to the website MijnZorgNet, which offers 23 virtual networks in which patients and their caregivers communicate. The networks are organized around specific patient categories. Successful examples that preceded the project are a digital in vitro fertilization (IVF) outpatient clinic [21,22] for couples receiving IVF treatment, and the website Parkinson Net [23] for people suffering from Parkinson's disease. Both

initiatives were started to enhance collaborative health care. Expected beneficial aspects of these projects were improved quality and efficiency of care [24]. Another concept that appears in the Health 2.0/Medicine 2.0 literature is "patient empowerment 2.0". This has been described as "the active participation of the citizen in his or her health and care pathway with the use of information and communication technologies" [25]. It is assumed that Health 2.0/Medicine 2.0 leads to empowerment of the patient, as patients have easier access to health-related information and thereby have better understanding of choices that can be made.

According to Hughes [16], no relevant differences exist between Health 2.0 and Medicine 2.0. Eysenbach [18] agreed but stated, "If anything, Medicine 2.0 is the broader concept and umbrella term which includes consumer-directed 'medicine' or Health 2.0". More and also more specific definitions of Health 2.0 and Medicine 2.0 exist [16,17]. However, these definitions seem to have evolved together with the increased use of the definitions and the different parties involved in Health 2.0 and Medicine 2.0. Ricciardi stated, "Everyone is trying to grasp what Health 2.0 exactly is" [26]. Does Health 2.0 refer to patients or to professionals or both? Does it focus on health care in general, or does it address specific aspects of health care like preventive or curative care, acute or chronic illness? Several authors concluded that there is no authoritative definition of the term yet, and Health 2.0 definitions and translations in practice remain murky and fragmented [27,28].

A clear definition is important for the development of new Health 2.0 or Medicine 2.0 initiatives and also for the comparability of new developments in research. Therefore, the aim of this study was to identify definitions of Health 2.0/Medicine 2.0 and to gain insight into recurrent topics associated with these labels.

Methods

We performed a systematic literature study to find unique definitions of Health 2.0/Medicine 2.0 and identify and recurrent topics discussed in conjunction with these terms.

Search strategy

First, we searched the following electronic databases: PubMed, Scopus, and CINAHL. For each database, we searched all available years through September 2009. Since there was no relevant MeSH term available for Health 2.0 or Medicine 2.0, we used the following search terms: health 2.0, health2.0, health20, medicine 2.0, medicine2.0, medicine20, Web 2.0, Web2.0, Web20 (Table 1). We scanned the reference lists for relevant articles (the snowball method), contacted individual experts in the field, and inquired after relevant publications.

Table 1. Search strategy for scientific literature

Database/ Search engine:	Search string	Details	Hits	Relevant[a]	Included[b]
PubMed	"health 2.0" OR"health2.0" OR "health20" OR "medicine 2.0" OR "medicine2.0" OR "medicine20" OR "Web 2.0" OR "Web2.0" OR "Web20"		179	12	7
CINAHL	"health 2.0" OR "health2.0" OR "health20" OR "medicine 2.0" OR "medicine2.0" OR "medicine20" OR "Web 2.0" OR "Web2.0" OR "Web20"		199	4	0
Scopus	(TITLE-ABS-KEY("health 2.0") OR TITLE-ABS-KEY("medicine 2.0")) OR (TITLE-ABS-KEY("health2.0") OR TITLE-ABS-KEY("medicine2.0")) OR (TITLE-ABS-KEY("health20") OR TITLE-ABS-KEY("medicine20"))		29	6	5
	(TITLE-ABS-KEY("Web 2.0") OR TITLE-ABS-KEY("Web2.0") OR TITLE-ABS-KEY("Web20")) AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "HEAL") OR LIMIT-TO(SUBJAREA, "NURS") OR LIMIT-TO(SUBJAREA, "MULT"))	Limited to subcategories: medicine, health professionals, nursing, multidisciplinary	126	3	2
Subtotal			533	25	14
Duplicates					5
Total			533	25	9

[a] Relevant: number of relevant articles based on title, abstract, and keywords

[b] Included: number of included articles based on full article

Second, we searched for gray literature on the Internet using the search engines Google, Bing, Yahoo, Mednar, and Scopus. Mednar and Scopus were used because they focus on scientific literature. Google, Bing, and Yahoo were used because these are the most widely used search engines [29,30]. We used the advanced search option, selected English as the preferred language, and turned the option for regional differences off. Based on earlier research [16], we expected a large number of results. Therefore we added a more specified search string query for Google, Yahoo, Bing, and Scopus (Table 2): "what is health 2.0", "what is health2.0", and "what is health20". For Medicine 2.0 we used: "what is medicine 2.0", "what is medicine20", and "what is medicine20". We studied the first 100 results in Google, Bing, and Yahoo as these search engines display results by relevance using a link analysis system or algorithms [31-33]. All searches in the gray literature were performed in November 2009.

Inclusion criteria

Subsequently, a combination of three of the authors (TB and LE and LS or SB) independently assessed the retrieved studies and gray literature for inclusion. Sources were included if a definition of Health 2.0 or Medicine 2.0 was identified. Disagreement over inclusion between the reviewers was resolved through discussion.

Table 2. Search strategy for gray literature

Database/ Search engine	Search string	Hits	Relevant[a]	Included[b]
Google	"health 2.0" OR "health2.0" OR "health20"	482,000	28	13
	"medicine 2.0" OR "medicine2.0" OR "medicine20"	155,000	24	16
	"what is health 2.0" OR "what is health 2.0" OR "what is health20"	99	29	25
	"what is medicine 2.0" OR "what is Medicine 2.0" OR "what is medicine 20"	33	14	14
Bing	"health 2.0" OR "health2.0" OR "health20"	328,000	4	4
	"medicine 2.0" OR "medicine2.0" OR "medicine20"	62,300	8	6
	"what is health 2.0" OR "what is health 2.0" OR "what is health20"	477	26	24
	"what is medicine 2.0" OR "what is medicine 2.0" OR "what is medicine 20"	31	12	11
Yahoo	"health 2.0" OR "health2.0" OR "health20"	466,000	17	9
	"medicine 2.0" OR "medicine2.0" OR "medicine20"	45,000	19	14
	"what is health 2.0" OR "what is health 2.0" OR "what is health20"	583	21	21
	"what is medicine 2.0" OR "what is medicine 2.0" OR "what is medicine 20"	121	14	12
Mednar	"health 2.0" OR "health2.0" OR "health20"	329	27	10
	"medicine 2.0" OR "medicine2.0" OR "medicine20"	12	13	5
Scopus	TITLE-ABS-KEY("what is health 2.0") OR TITLE-ABS-KEY("what is health2.0") OR TITLE-ABS-KEY("what is health20")	23	3	0
	TITLE-ABS-KEY("what is medicine 2.0") OR TITLE-ABS-KEY("what is medicine2.0") OR TITLE-ABS-KEY("what is medicine20")	0	0	0
Subtotal		1,540,008	262	184
Duplicates				149
Total				35

Data extraction

TH and LE independently assessed the included studies and gray literature and extracted unique definitions. A predesigned table was used to ensure standardized data extraction. For each definition we noted author, source, and year (Table 3). After completing the table, we used the constant comparison method to explore possible topics of Health 2.0 and Medicine 2.0 [34]. We independently analyzed the definitions and identified recurrent topics by using "coding". Described by Strauss and Corbin, coding is an analytical process through which concepts are identified and dimensions are discovered in data [35]. The results are displayed in Table 4.

Results

We scanned a total of 1937 articles, 533 found in scientific databases and 1404 in the gray literature (Tables 1 and 2). We selected 287 articles, 25 peer reviewed articles, and 262 non-scientific articles for further analysis. After selection and removing duplicates, we distinguished 46 unique definitions of Health 2.0 or Medicine 2.0 in 44 articles (Table 3).

Table 3. Definitions of Health 2.0 and Medicine 2.0

Author, source, and whether found in scientific literature[a] or gray literature[b]	Year of publication	Definition
Aller RD, et al [36] (Gray)	2007	The term, boiled down to its most basic definition, refers to the evolution of technologies and the medical industry itself to create the next generation of health care for consumers, providers, and payers alike. The term is a take on Web 2.0, which refers to the evolution of the Internet from a tool used essentially for information gathering to one used for collaboration and social interaction.
Bos L, et al [25] (Scientific)	2008	Health 2.0 is user generated Health care. What is foreseen is that the self-care information tool of the future will be a combination between the patient's observation record and the Internet, with the doctor and the patient positioned together at the intersection but not having to pay attention to the technology.
Bos L, et al [37] (Scientific)	2008	Health 2.0 defines the combination of health data and health information with (patient) experience through the use of ICT, enabling the citizen to become an active and responsible partner in his/her own health and care pathway.
Bourre N [38] (Gray)	2009	Social media and conversations related to health care, where all stakeholders are on the same level of the playing field.
Castilla V [39] (Gray)	Unknown	Medicine 2.0 is about realizing the potential of today's technology in health care. Medicine 2.0 is about working together. Medicine 2.0 is about getting closer to colleagues and patients.
Conn J [15] (Scientific)	2007	The health care derivate of the far more ubiquitous "Web 2.0."
Doherty I [27] (Scientific)	2008	Web 2.0 Technologies provide members of the health community – health professionals, health consumers, health carers, and medical and medical and health science students – with new and innovative ways to create, disseminate, and share information both individually and collaboratively. This phenomenon has been termed Health 2.0. There is no authoritative definition of the term yet. Health 2.0 is in its infancy and we should be careful not to assume that a revolution has occurred in health care as a result of these new technologies and their various affordances.
Dolan F [40] (Gray)	2007	Health 2.0 is the application of Web 2.0 technologies in the area of health, while Medicine 2.0 is the use of Web 2.0 technologies in the area of medicine.
Dubay A [41] (Gray)	2007	Health 2.0 is the evolution of health care as a result of consumer empowerment. Its definition ranges from "applied Web 2.0 technology to health care" to "the next generation health care delivery".
Eysenbach G [18] (Scientific)	2008	Medicine 2.0 applications, services, and tools are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and/or semantic web and virtual-reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups. Or in broader concept: medicine also stands for a new and better health system, which emphasizes collaboration, participation, apomediation, and openness, as opposed to the traditional, hierarchical, closed structures within health care and medicine. Medicine 2.0 is the broader concept and umbrella term, which includes consumer-directed "medicine" of Health 2.0.
Eytan T [42] (Gray)	2008	Health 2.0 is participatory health care. Enabled by information, software, and community that we collect or create, we the patients can be effective partners in our own health care, and we the people can participate in reshaping the health system itself.

Author, source, and whether found in scientific literature[a] or gray literature[b]	Year of publication	Definition
Facebook Health 2.0 Group [43] (Gray)	2007	Health 2.0 is the mashing of Web 2.0 concepts and tools to health care industry, including social networking to promote better collaboration between patients, their caregivers, medical professionals, and others involved in the health care industry.
Flock B [44] (Gray)	2008	Health 2.0: Expand initial Health care 2.0 concept (Web 2.0 features to health care; ratings, search, social communities, and consumer tools) to include entire Health ecosystem (payers, providers, employers, consumers, life sciences entities, government: anyone who can contribute meaningful data.)
Furst I [45] (Gray)	2008	Health 2.0 is participatory health care characterized by the ability to rapidly share, classify, and summarize individual health information with the goals of improving health care systems, experiences, and outcomes via integration of patients and stakeholders.
Gavgani VZ, et al. [70] (Scientific)	2008	Medicine 2.0 is the latest approach to ensure better health system and well-being of the humanity, in other words, "health for all", and a healthy community. The development of Medicine 2.0 grossly depends on the application of Web 2.0 sciences.
Goel V [46] (Gray)	Unknown	Health 2.0 is the use of social media and other technologies to improve communication in health care. These platforms may be used to connect patients with patients, doctors with other professionals, or patients with doctors. The Health 2.0 movement is about enhancing communication to improve the focus and results of the health system on the patients it serves.
Goreman J, et al. [47] (Gray)	2008	Health 2.0: The combination of content and community.
Halper R [48] (Gray)	2007	The empowerment of the individual to have access to detailed objective health care information primarily, though not exclusively, using search engine sites and like-minded communities of patients and physicians.
Hawker M [49] (Gray)	2008	Health 2.0 is a continually evolving cycle of health care innovation enabled by the empowerment of the public, patients, health care providers and suppliers, and researchers through increased collaboration, participation, apomediation, feedback and transparency of value-enabled health care interactions.
Healthcaremanagementblog [50] (Gray)	2008	Health 2.0 aka Medicine 2.0 aka eHealth, can be broadly defined as "applications, services, and tools are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies as well as semantic web and virtual reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups".
Holt M [51] (Gray)	2007	The use of social software and lightweight tools to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health.
Hughes B [16] (Scientific)	2008	Health 2.0 and Medicine 2.0 were found to be very similar and subsume five major salient topics: (1) the participants involved (doctors, patients, etc); (2) its impact on both traditional and collaborative practices in medicine; (3) its ability to provide personalized health care; (4) its ability to promote ongoing medical education; (5) its associated method- and tool-related issues, such as potential inaccuracy in end user-generated content. Difference Health 2.0 and Medicine 2.0 with eHealth, the key distinctions are made by the collaborative nature of Health 2.0 and Medicine 2.0.
Jessen W [52] (Gray)	2008	Medicine 2.0 is the science of maintaining and/or restoring human health through the study, diagnosis, and treatment of patients utilizing Web 2.0

Author, source, and whether found in scientific literature[a] or gray literature[b]	Year of publication	Definition
		Internet-based services, including Web-based community sites, blogs, wikis, social bookmarking, folksonomies (tagging) and Really Simple Syndication (RSS), to collaborate, exchange information, and share knowledge. Physicians, nurses, medical students, and health researchers who consume Web media can actively participate in the creation and distribution of content, helping to customize information and technology for their own purposes. Health 2.0, a new concept of health care, also utilizes Web 2.0 Internet-based services but is focused on health care value (meaning outcome/price). Patients, physicians, providers, and payers use competition at the medical condition level over the full cycle of care as a catalyst for improving safety, efficiency, and quality of health care delivery. The goal of both of these movements is the delivery of optimal medical outcomes though individualized care.
Levine C [53] (Gray)	2009	Health 2.0 = a noun that describes user-generated health care content. Spurred by sites like YouTube, Facebook, and Wikipedia, millions are logging on to contribute information and opinions on everything from medications, health professionals, treatment options, side effects, flu pandemics, and best drug practices.
Mesko B [17] (Gray)	2007	Medicine 2.0 = Web 2.0 + medicine (focusing on doctor-patient communication and technologies). Health 2.0 = Web 2.0 + health care (focusing on shaping health care with Web 2.0 tools and concepts).
Maun C [54] (Gray)	2009	Health 2.0 can be broadly defined as interactive applications, services, and tools that are Web-based services for health care consumers, caregivers, patients, and health professionals.
Moturu ST, et al. [55] (Scientific)	2008	Like the Web 2.0 revolution changed the user from a passive consumer to an active contributor, a similar metamorphosis being termed as Health 2.0 or Medicine 2.0 would extend the role of information seeking users to include dissemination of experiences and acquired knowledge.
Rampy A [56] (Gray)	2008	Health 2.0 = the merging of social media into health care.
Randeree E [3] (Scientific)	2008	Health care 2.0 can be defined as a network of (Web 2.0) applications and services that empower the user and are delivered through the web as a platform.
Ricciardi L [26] (Gray)	2008	Its grassroots push through which patients are using social networks and other tools to generate their own health data and transform their role vis a vis the health care system. Quite honestly, everyone is still trying to figure out exactly what Health 2.0 is.
Richlovsky P [58] (Gray)	2007	Basically, Health 2.0 is a takeoff of Web 2.0, and it alludes to health websites that incorporate Web 2.0 principles of encouraging user-generated and user-owned content, participation, and community-building in rich, interactive environments.
RN Central [57] (Gray)	2008	Health 2.0 embraces the idea of bringing health care into the community of medical professionals, patients, and those in the health care industry together with technology and the Internet to provide the best possible health care environment.
Sarashon-Kahn J [59] (Gray)	2007	Social media on the Internet are empowering, engaging, and educating consumers and providers in health care. This movement, known as Health 2.0, can be defined as: The use of social software and its ability to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health.

Author, source, and whether found in scientific literature[a] or gray literature[b]	Year of publication	Definition
Sharp J [60] (Gray)	2009	Health 2.0 evolved more recently and focuses on Web 2.0 tools, especially social media tools, and their use in health care.
Shreeve S [61] (Gray)	2007	Health 2.0: New concept of health care wherein all the constituents (patients, physicians, providers, and payers) focus on health care value (outcomes/price) and use disruptive innovation as the catalyst for increasing access, decreasing cost, and improving the quality of health care.
Spoetnik L [71] (Gray)	2009	Medicine 2.0 is the use of a specific set of Web tools (blogs podcasts, tagging, search, wikis, etc.) by actors in health care, including doctors, patients, and scientists, using principles of open source and generation of content by users and the power of networks in order to personalize health care, collaborate, and promote health education.
Stoakes U [62] (Gray)	2008	Health 2.0: A new wave of innovation in health care as a result of changing trends in technology, consumer empowerment, and growing entrepreneurialism at a time when the health care system is spiraling out of control. These converging trends have created an environment for entrepreneurs, start-up companies, innovative thinkers, health professionals, and consumers to rethink how to solve today's biggest health care challenges. Health 2.0 is about coming up with new ideas and rethinking what's possible.
Susheel-Ommen J [3] (Gray)	2007	Health 2.0 derives its definition from the definition of Web 2.0, where the technologies used allowed intelligent interaction between the users and the deployed solutions. Currently available technologies allow users to actively participate and contribute to the information that is front-ended using Web interfaces.
Tenderich A [64] (Gray)	2009	It's both an explosion in new Web-based personal health technologies and a whole new way of involving consumers in the health care system.
Torrey T [65] (Gray)	2008	Medicine 2.0 or Health 2.0 are terms used to describe the massive Internet-sharing of health and medical information among everyone with interest, from health and medical professionals, to patients, to caregivers, to the businesses (pharmaceutical manufacturers, health insurance) which support them. The two terms, Medicine 2.0 and Health 2.0, are often used interchangeably. However, there is a distinction. Medicine 2.0 usually refers to the science of medicine and the practice of treating or curing patients. Health 2.0 is focused on the business of health in general including the delivery, the quality, the safety, and the cost or efficiency of the people, a practice, or facility.
Venn D [66] (Gray)	2008	Health 2.0 is an emerging concept of health care that uses Web 2.0 technologies to promote collaboration between patients, physicians, health care professionals, and other members of the health community. Its application is ever-changing, and the evidence for its effectiveness is still raw, but there’s a lot of potential for this type of new technology to improve mental health education and mental health care.
Weisbaum W [67] (Gray)	2007	Health 2.0 is the use of movement to harness the technology of Web 2.0 for the delivery of the next generation of health care services.
Williams P [68] (Gray)	Unknown	Health 2.0 is the use of Web technology to deliver consumer-driven health services. It uses the same Web 2.0 technology that drives the successful Internet services such as Ebay, Facebook, Expedia, and Amazon.

Author, source, and whether found in scientific literature[a] or gray literature[b]	Year of publication	Definition
Wright-Mark S [69] (Gray)	2008	Health 2.0 is a new concept of health care that employs social software and other Web-based tools to promote collaboration between patients, their caregivers, medical professionals, and other stakeholders in health care to create a better, more knowledgeable and cost effective environment for better well-being.

[a] Located with search of the following databases: PubMed, Scopus, and CINAHL
[b] Located using the search engines Google, Bing, Yahoo, Mednar, and Scopus

The length of the definitions varied from 7 to 105 words. We found 42 definitions describing Health 2.0 [3,15-18,25-27,36-69] and two definitions describing Medicine 2.0 [70,71]. Of the 44 articles included, 8 included definitions of both Health 2.0 and Medicine 2.0 [16-18, 40,50,52,55,65]. From these 46 definitions, we identified 7 main recurrent topics: patients, Web 2.0/technology, professionals, social networking, change of health care, collaboration, and health information/content (Table 4). In the following paragraphs we describe these recurrent topics from these definitions in more depth.

Table 4. Recurrent topics of Health 2.0 and Medicine 2.0

Author and definition of Health 2.0 (H2) and/or Medicine 2.0 (M2)			Topics						
Author	H2	M2	Patients and consumers	Web 2.0	Professionals	Social Networking	Change	Collaboration	Health information or content
Aller RD, et al. [36]	*		*	*	*	*	*	*	*
Bos L, et al. [25]	*		*	*	*				
Bos L, et al. [37]	*		*	*					*
Bourre N [38]	*					*			
Castilla V [39]	*		*	*				*	*
Conn J [15]	*			*					
Doherty I. [27]	*		*	*	*		*	*	*
Dolan F [40]	*	*		*					
Dubay A [41]	*		*	*			*		
Eysenbach G [18]	*	*	*	*	*	*	*	*	
Eytan T [42]	*		*	*		*	*		*
Facebook Health 2.0 Group [43]	*		*	*	*	*		*	
Flock, B [44]	*		*	*	*	*			*
Furst I [45]	*		*		*				*
Gavgani VZ, et al. [70]		*	*	*					
Goel V [46]	*		*	*	*	*			
Goreman J, et al. [47]	*					*			*
Halper R [48]	*		*		*	*			*
Hawker M [49]	*		*		*		*	*	
Health care managementblog [50]	*	*	*	*	*	*		*	
Holt M [51]	*		*	*	*	*		*	
Hughes B [16]	*	*	*		*			*	
Jessen W [52]		*		*	*	*		*	

Author and definition of Health 2.0 (H2) and/or Medicine 2.0 (M2)			Topics						
Author	H2	M2	Patients and consumers	Web 2.0	Professionals	Social Networking	Change	Collaboration	Health information or content
	*		*	*	*		*		
Levine C [53]	*		*						*
Mesko B [17]	*		*	*	*		*		
		*	*	*	*		*		
Maun C [54]	*		*		*				
Moturu ST, et al. [55]	*	*					*		
Rampy A [50]	*					*			
Randeree E [3]	*		*	*					
Ricciardi L [26]	*		*			*			
Richlovsky P [58]	*			*		*			*
RN Central [57]	*		*	*	*				
Sarashon-Kahn J [59]	*		*		*	*		*	
Sharp J [60]	*			*		*			
Shreeve S [61]	*		*		*		*		
Spoetnik L [71]		*	*	*	*	*		*	*
Stoakes U [62]	*		*	*	*		*		
Susheel-Ommen J [63]	*		*	*		*			*
Tenderich, A [64]	*		*	*			*		
Torrey T [65]	*	*	*		*				*
Venn D [66]	*		*	*	*		*	*	
Weisbaum W [67]	*			*			*		
Williams P [68]	*			*					
Wright-Mark S [69]	*		*	*	*	*		*	

Patients and consumers

The first main topic was "patients" or "consumers of health care", which was found in 35 definitions. Of these, 12 included mention of either increased participation or empowerment of patients. The following terms or phrases were identified: increased consumer/patient participation [18,27,49,50,58], patients can actively participate [63], and participatory [42,45], patient empowerment or consumer empowerment [41,49,59,62]. The other 23 mentioned only patient or consumer involvement and not the effects.

Web 2.0/Technology

The second main topic that appeared in 32 definitions from 30 articles was "Web 2.0" or "technology". Terms varied from "Web 2.0" [3,15,17,36,43,44,46,52,55,57,58,60,62,67,70], to "Web 2.0 technology" [18,27,40,41,50,66,68], "technology" [25,39,62-64], "software" [42,51], "Web (based) tools" [69,71], and "ICT (information and communication technology)" [37]. Web 2.0 was seen as the total of available technologies that stakeholders could use for communication and for sharing information. One definition mentioned "mashing" of Web 2.0 concepts and tools [43]. "Mashing" was seen as combining two or more Web 2.0 sources to create a new one. Other definitions indicated that the concept of Health 2.0 originated from a combination of the concepts "health" and "Web 2.0" [17,40].

Professionals

The third topic that was identified concerns "professionals" or "caregivers", and was found in 26 definitions. Of the 46 included definitions, five mentioned increased participation or empowerment of professionals. The following terms were found: "professional empowerment" [49,52,59], "empowerment of the individual" [48], and "empowerment of the user" [3]. Besides patients and professionals, other stakeholders were mentioned. However, they were mentioned less frequently and therefore not included in Table 4 as individual topics. The following stakeholders were mentioned: payers or providers [36,44,52,61], medical and health science students [27,52], biomedical researchers [18,44,49,50,52,71], entrepreneurs [62,65], and government [44]. Other authors were less specific with regard to stakeholders. They included "all stakeholders" [38] or "others" [43,51,57,66].

Social networking

The fourth topic, the emergence of online communities and social networking, was reflected in 22 definitions. This was described using different terminology. Definitions referred to "online communities" [42,47,48,51,52,58,66], "social communities" [44], "networks" [71], whereas others referred to "online social networks" or "social networking" [18,26,36,43,50,59], "social interaction" [36], "interactive environments" [58], or "intelligent interaction" [63]. Other definitions focused more on technology: the terms used were "social media tools" [60], "social media", or "social software" [38,46,56,59,69]. Two authors mentioned "transparency" or "openness" [18,49]. An additional 2 definitions suggested that "sharing" or "online sharing" of medical information was part of Health 2.0 or Medicine 2.0 [45,65].

Change of health care

Fifth, we found that change of health care was described by 15 definitions. According to the definitions, Health 2.0 means change of health care: "a whole new way of involving consumers in the health care system" [64], "next generation of health care services" [67], "new and better health system" [18], "new concept of health care" [52], "all constituent focus on health care value and on improving safety, efficiency and quality of health care" [61], "shaping health care with Web 2.0 tools" [17], and "new wave of innovation" [62]. Change was described differently: "reshaping health care" [17,42], "ever changing" [66], "continually evolving cycle" [49], "evolution of technology and medical industry" [36], "volution of health care" [41]. Change was also described as "revolutionary" [55], while another author stated, "we should be careful not to assume that a revolution has occurred in health care" [27]. We also found one author who referred to "user generated health care" [25].

Collaboration

The sixth topic, mentioned in 14 definitions, was collaboration. In the Health 2.0 era, patients will actively contribute to their own care process. Collaboration between professionals and patients may improve. Terms varied from "collaboration" [18,36,43,49,51,59,66,69], "collaboratively" [27],

"collaborate" [52,71], "collaborative practices" [16], and "collaborate and share knowledge" [70] to "working together" [39]. There were also other aspects described with regard to the relationship among stakeholders. Patients would transform their role in health care [26] and would be on the same level of playing field as other stakeholders [38]. A role change of patients and professionals was also indicated. For example, the following phrase was used: "doctor and patient positioned together" [37]. Patients were described as "active contributors" [55], "active and responsible partners" [25], or "active partners" [42]. Another author mentioned "integration of patients and stakeholders" [45].

Health information or content

Seventh and last, there was mention of health information or content in 14 definitions. Terms varied from "information", "health information", or "medical information" [27,36,37,42,45,48, 53,63,65] to "content" [47], "data" [26,44,71], and "user owned content" [58].

Discussion

This literature search resulted in 46 unique definitions in 44 articles of Health 2.0/Medicine 2.0 in scientific databases and gray literature on the Internet. We distinguished seven recurrent topics: Web 2.0/technology, patients, professionals, social networking, health information/content, collaboration, and change of health care. This study showed that the use of the terminology differed among the definitions mentioned in literature. The term Health 2.0 was included in 42 definitions, 10 definitions mentioned Medicine 2.0, and 6 definitions described Health 2.0 and Medicine 2.0 as equal. There were 36 definitions that only mentioned the term Health 2.0, and only 4 definitions that described Medicine 2.0. Although some authors indicated that little or no differences existed between the two terms [16,18,27,55], others saw differences, for example that Medicine 2.0 is focused on the relation between professionals and patients whereas Health 2.0 is focused on health care in general [17,52,65]. As most definitions described Health 2.0, this term may be more widely used and accepted than Medicine 2.0.

Overall, we found that the term Web 2.0 was mentioned often: 33 authors used the term directly in the definition, which suggests that they accepted this concept. However, others state that Web 2.0 does not exist at all [72]. Authors' interpretations of the meaning of Web 2.0 influenced their definitions of Health 2.0/Medicine 2.0 profoundly. We generally distinguished two meanings of Web 2.0. The first meaning is that Web 2.0 is a set or "mashing" (i.e. a combination) of technological developments [51,58]. The second meaning is that Web 2.0 is a new generation of the Internet where interaction is important, with more user-generated content that empowers people. In this interpretation, technology, or the mashing of different technologies, is only a tool, and Web 2.0 is more than technology. These meanings result in different definitions of Health 2.0/Medicine 2.0. A number of definitions referred to the technological developments embedded in health care, whereas other definitions stated that Health 2.0/Medicine 2.0 is a new generation of health care. We believe Web 2.0 is a facilitator for Health 2.0/Medicine 2.0, but not a necessity.

Indeed, patients can still access health related information without Web 2.0; for example, a patient can go to a library and become well-informed without Web 2.0 technology. However, this would be far more difficult than becoming well-informed through the use of Web 2.0 technology. Second, the topic of stakeholders reflects who the main players are in the field of Health 2.0/Medicine 2.0. The two main stakeholders we distinguished were patients or consumers, mentioned in 35 definitions, and professionals or caregivers, mentioned in 26 definitions. Interestingly, other stakeholders such as payers of health care, scientists, students, and entrepreneurs were mentioned less frequently, whereas the government was only mentioned once. This is particularly interesting as the government has great influence on health care and changes in health care. Apparently the government is not yet an active party in the development of Health 2.0/Medicine 2.0. Also interesting was that most definitions focused on the relation between patients and professionals. With Health 2.0/Medicine 2.0, patients and professionals were seen to collaborate, with patients transforming their role in health care using social networks and access to health information. Moreover, other relationships might also change; for example, the appearance of online communities could change the relationship between health professionals and specific groups of patients. This has been termed collaborative health care [18]. Finally, it is expected that Health 2.0/Medicine 2.0 will lead to change of health care. Expectations concerning the speed of this change ranged from a "gradual shift" [27], an "ever changing" [66] or "continuous interactive process" [49] to "revolution" [55]. However, we advise caution in assuming that a revolution has taken place [27]. It may be that communication, information exchange, and patients' contribution to his or her care has improved or accelerated, but according to Engelen [8], no fundamental changes in health care have yet occurred. Authors of a Health 2.0/Medicine 2.0 definition generally seemed to approach the definition from their own perspective. For example, patients or patient federations saw patients as the main stakeholder and focused on empowerment of the patient. That is, definitions may be influenced by different stakeholders' agendas. Therefore, it is important for future Health 2.0/Medicine 2.0 researchers to incorporate all stakeholders and thereby include all possible views and perspectives.

Limitations

Our study has some limitations. First, we found 46 unique definitions, mostly in the gray literature, using the Internet. Only 9 definitions were found in peer-reviewed articles in the scientific literature. This can be explained by the fact that Health 2.0/Medicine 2.0 is a relatively new concept and is still developing. However, it is important to realize there is no evidence-based method available to determine the quality of online content yet. Consequently, proper assessment of the value of the definitions we found was not possible. Second, it appeared that searches using Google, Bing, and Yahoo showed many results. Although these search engines displayed results by relevance using algorithms and ranking systems, we may have missed unique definitions as we only studied the first 100 results. Finally, the exact way search engines display results remains unclear. The process can be seen as a black box. As a result, reproduction of searches is far from optimal, as the results literally change every second. Therefore, one might question the suitability

of these search engines for scientific research. However, by combining the results of Google, Bing, and Yahoo and using four search queries, we believe we found the majority of all relevant definitions in the gray literature.

Conclusion

Health 2.0/Medicine 2.0 is still a developing concept. Our study identified 46 unique definitions of Health 2.0 and Medicine 2.0 with seven recurrent topics: Web 2.0/technology, patients, professionals, social networking, health information/content, collaboration, and change of health care. There is no general consensus of the definition of Health 2.0/Medicine 2.0 yet. We hope that this study will contribute to building the concept of Health 2.0/Medicine 2.0 and facilitate future discussion and research to achieve a clear conceptual framework.

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3

Use of Social Media by Western European Hospitals: Longitudinal Study

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Abstract

Background: Patients increasingly use social media to communicate. Their stories could support quality improvements in participatory health care and could support patient-centered care. Active use of social media by health care institutions could also speed up communication and information provision to patients and their families, thus increasing quality even more. Hospitals seem to be becoming aware of the benefits social media could offer. Data from the United States show that hospitals increasingly use social media, but it is unknown whether and how Western European hospitals use social media.

Objective: To identify to what extent Western European hospitals use social media.

Methods: In this longitudinal study, we explored the use of social media by hospitals in 12 Western European countries through an Internet search. We collected data for each country during the following three time periods: April to August 2009, August to December 2010, and April to July 2011.

Results: We included 873 hospitals from 12 Western European countries, of which 732 were general hospitals and 141 were university hospitals. The number of included hospitals per country ranged from 6 in Luxembourg to 347 in Germany. We found hospitals using social media in all countries. The use of social media increased significantly over time, especially for YouTube (n=19, 2% to n=172, 19.7%), LinkedIn (n=179, 20.5% to n=278, 31.8%), and Facebook (n=85, 10% to n=585, 67.0%). Differences in social media usage between the included countries were significant.

Conclusions: Social media awareness in Western European hospitals is growing, as well as its use. Social media usage differs significantly between countries. Except for the Netherlands and the United Kingdom, the group of hospitals that is using social media remains small. Usage of LinkedIn for recruitment shows the awareness of the potential of social media. Future research is needed to investigate how social media lead to improved health care.

Introduction

Social media are defined as a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and they allow the creation and exchange of user-generated content [1]. Social media allow individuals to participate in online social networks and turn communication into interactive dialogue, using highly accessible and scalable communication applications [2]. Of all young Internet users (18-24 years of age) in the European Union, 80% use social media [3]. In the Netherlands, this percentage is even higher, with 91% using social media [3]. Facebook and Twitter are well-known examples of social media, which have become mainstream social technologies [4]. Facebook has over 800 million active users [5]. For comparison, the United States has 310 million inhabitants [6]. One of the success factors of social media is that many are free of charge. Social media play an increasingly important role in our society, and they are being used for a large variety of purposes, varying from finding a job or an employee to finding a partner or planning a trip. Also, a growing number of people are using mobile devices such as smartphones and tablet computers, which allow them to use social media from any place, at any time [1].

Social media empower users by allowing them to communicate effectively and have access to all kinds of information. Not only individuals use social media; companies use them too. It helps them to listen better to customers to hear what they want. Barnes and Mattson studied use of blogs and Twitter by the 500 largest corporations in the United States [7]. They found a steady adoption of blogs and an explosive growth of Twitter. As these companies have great influence on the commercial sector, it is expected that social media will become more important in the business world.

In health care, patients increasingly use social media to communicate and share information. This is one of the fundamentals of what is described as Health 2.0 or Medicine 2.0 [8]. Patients share their stories and information on social media, which are rapidly indexed by search engines like Google and can be found easily. Seeing that many patients start by performing a Google search, it seems relevant for hospital organizations to be active on social media. For example, 64% of all respondents of an online questionnaire among patients in the United States start by performing a search to analyze their condition [9]. Another reason why hospital organizations should embrace social media is that it may contribute to quality improvements in health care. Active use of social media not only speeds up communication and improves information provision for patients; it allows caregivers to engage patients in the delivery of care, and for caregivers and patients to make decisions collaboratively and improve their relationship [10]. In this way, using social media improves patient-centered care [11]. There are also beneficial aspects for the hospital organization itself. Several studies reported that social media can improve communication among staff, facilitate networking, attract visitors to the hospital's website, build the hospital's brand, and be used for recruitment for research projects [12,13].

A descriptive study performed in the United Kingdom found that 40% of the 152 health care organizations they studied used one or more types of social media, but that there was little interaction with online visitors (e.g., patients) [14]. Also, many organizations were simply "seeding" information. In the United States, the use of social media by hospitals has been noted. Bennett documented that 674 hospitals had a Twitter account and 448 were on YouTube [15]. Considering that the United States has a total of 5000 hospitals, around 15.7% of all hospitals in the United States are on Twitter, 20.3% are on Facebook, and 10.9% are on YouTube [16]. However, it is unknown whether and how Western European hospitals use social media. Therefore, the target of this study was to identify the extent to which European hospitals use social media.

Methods

In this longitudinal study, we explored the use of social media by hospitals in 12 Western European countries through an Internet search.

Inclusion criteria

We included the following Western European countries: the Netherlands, Belgium, Luxembourg, Germany, Austria, Switzerland, the United Kingdom, Ireland, Norway, Sweden, Finland, and Denmark. To retrieve a comprehensive list of hospitals for each country, we searched for lists of hospitals with detailed information on Wikipedia and the Hospitals Worldwide website [17,18]. Second, we contacted colleagues from the included countries and asked for official lists of hospitals. Third, we consulted country-specific websites with detailed information. Fourth and last, we used Google and each hospital's website to find additional information such as contact information or the number of beds. We included only hospitals with a website and at least 200 beds. If hospitals were part of a larger hospital organization with a central website, we explored the central website only and counted these hospitals as 1 hospital.

Variables

For each hospital we recorded the following characteristics: official name, address, country, province or state, email, number of beds, and number of hospitals included in the organization. Since no scientific evidence was available on the popularity of different social media, we used information from websites and infographics to decide which social media were most popular and needed to be included in the study [19,20]. We gathered data about the following social media: YouTube, Twitter, Facebook, LinkedIn, and blogs (weblogs). We defined blog by the presence of the following characteristics: reverse chronological order of publication, regular updates (>1 per month), and the possibility to post comments. Facebook has different types of pages. In this study, we distinguished between company pages and group pages. For each medium, we searched for relevant data on use such as the number of friends or followers, the number of videos or tweets, and the date of registration. For each medium, we recorded whether the media could be found via the hospital's website.

Data collection

Between April 2009 and July 2011, we collected data for each country during the following three time periods: T1 (April to August 2009), T2 (August to December 2010), and T3 (April to July 2011). YouTube accounts, Twitter accounts, and blogs were measured at T1, T2, and T3. For Facebook and LinkedIn, we performed two measurements, at T2 and T3. Two researchers collected the data. A predefined search protocol was used, containing a 3-step search strategy. First, we visited the hospital's website and searched for social media. We also used the website's search function (if available). Second, we searched for the hospital's name within the different types of social media such as YouTube. Third and last, we used Google for more specific search queries, such as the hospital's name and Twitter. Table 1 presents the search protocol. Before the official start, the two researchers involved in the search discussed the results for 20 hospitals. Since all variables in this study are unambiguous (e.g., number of beds, Twitter account: "yes" or "no"), no relevant differences or issues appeared.

Table 1. Search protocol for data collection

Step	Protocol
1	Select hospital from list.
2	Visit official website and add contact information to table. Find using standard search tool (i.e., Google).
3	Record number of beds (total). Include hospitals with >200 beds.
4	If included, proceed to next steps.
5	Add general information.
6	Look for different types of social media on hospital's website and add to table.
7	Use search option on hospital's website and search the terms *YouTube*, *movie*, *film*, *Twitter*, *Facebook*, *blog*, *LinkedIn*, and *weblog*. Add all new social media to the table.
8	Visit Twitter.com, Youtube.com, Facebook.com, and LinkedIn.com and search on hospital's official name. Add all new social media to the table.
9	Use specific search queries in Google, e.g., the hospital's name AND *Facebook*. Add all new social media to the table.
10	Add other relevant information for all types of social media, e.g., number of friends and followers, date of registration.

Data validation

We contacted all organizations with the request to validate the results for their hospital. We sent emails to each hospital's general email address as stated on their official website, most likely on the contact page. The email contained a description of this study by the Radboud REshape & Innovation Center, University Nijmegen Medical Centre, and a unique link to an online database. Receivers were able to make changes or add information or comments. We sent 873 email requests. Of these, 45 messages (5%) were returned as undeliverable, and 44 hospitals validated the results (5%).

Analysis

We used descriptive statistics to describe the basic features of our data and the use of social media by the included hospitals. We calculated percentages, means, and standard deviations for

normally distributed data, and medians and interquartile ranges for nonnormally distributed data. Cochran Q test was used to analyze the differences in social media usage between the three measurements within individual countries. In case of significant differences, we used the McNemar test for post hoc testing. Furthermore, we analyzed the differences in social media usage between countries at T3 by using the chi-square test. Finally, we used the Wilcoxon rank test to analyze the nonnormally distributed data for number of videos, views, and followers between T2 and T3 within the included countries.

Results

In total we looked at 873 hospitals from 12 Western European countries: 732 general hospitals and 141 university hospitals. The number of included hospitals per country ranged from 6 in Luxembourg to 347 in Germany. The mean number of beds per hospital was 544. Table 2 presents general characteristics of the hospitals.

Table 2. Hospitals included in the analysis and their general details

Country[a]	Number of hospitals			Number of beds, mean (SD)
	Total	General hospitals	University hospitals	
NL	88	80	8	549 (278)
BE	91	79	12	450 (261)
LU	6	5	1	363 (139)
DE	347	314	33	533 (445)
AT	25	19	6	775 (587)
CH	41	39	2	389 (232)
UK	175	123	52	624 (282)
IR	28	21	7	392 (192)
NO	17	11	6	480 (238)
SE	22	17	5	698 (511)
FI	9	7	2	697 (544)
DK	24	17	7	551 (286)
Total	873	732	141	544 (376)

[a] NL = the Netherlands, BE = Belgium, LU = Luxembourg, DE = Germany, AT = Austria, CH = Switzerland, UK = United Kingdom, IR = Ireland, NO = Norway, SE = Sweden, FI = Finland, DK = Denmark

YouTube

YouTube accounts were found in 10 countries (Table 3). At T3, we found significant differences in the percentage of YouTube usage ($\chi 2$ 11 = 73.9, P < .001). The Netherlands (38%, n=33) and the United Kingdom (35%, n=62) had the highest percentage of hospitals with a YouTube account. During the research period, the percentage of YouTube accounts increased significantly (Table 3). The median number of videos per YouTube account at T3 was 7 (Table 5).

Twitter

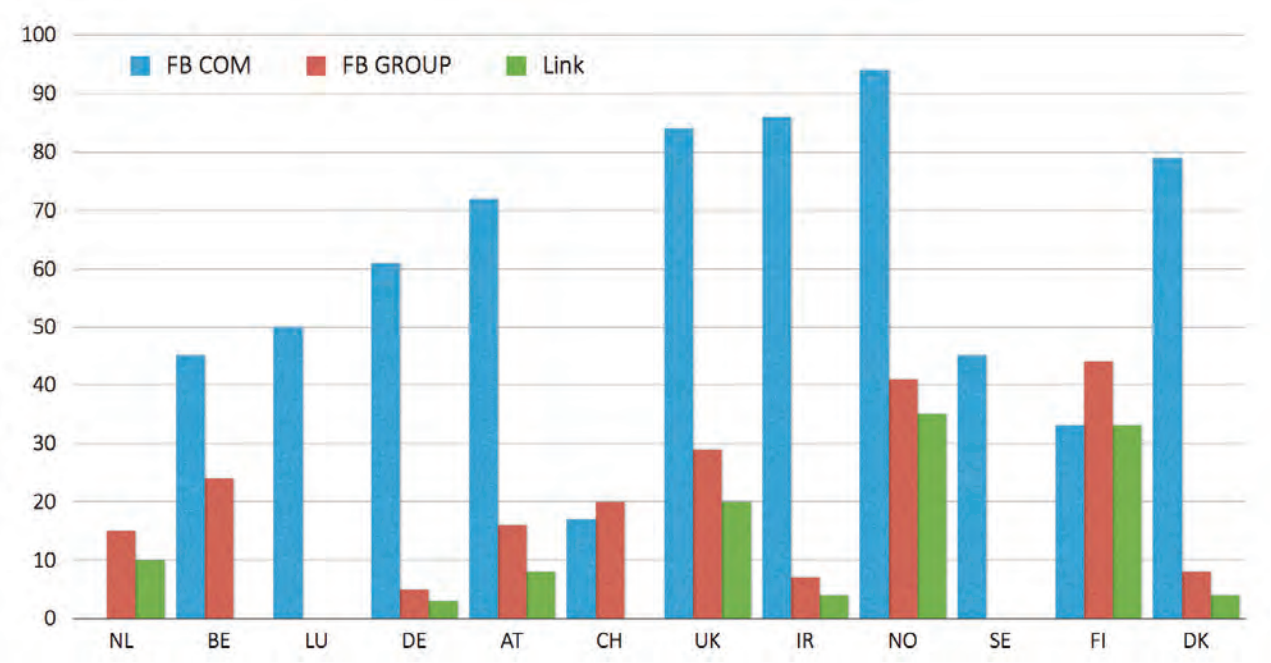
Twitter accounts were found in 8 of 12 countries (Table 3), with significant differences between countries ($\chi 2$ 11 = 209.2, P < .001) at T3. The Netherlands (56%, n=49), the United Kingdom (39%,

n=68), and Norway (47%, n=8) had the highest percentages of hospitals with a Twitter account. The median number of followers for all countries at T3 was 271 (Table 5). We identified 1 hospital with 3300 followers.

Facebook

Facebook accounts were found in all countries, ranging from 15% (n=13) in the Netherlands to 93.1% (n=163) in the United Kingdom (Table 4). At T3, there was a significant difference between all countries in the percentage of Facebook usage ($\chi 2$ 11 = 202.1, P < .001). Facebook usage increased significantly in 11 countries. Two types of Facebook accounts were found: company profiles and group pages (Figure 1). The number of Facebook group pages was lower, ranging from 0% in Luxembourg to over 40% in Finland and Norway. Apart from 2 countries (Norway and Finland), having a Facebook page accessible through the hospital's website was an exception (Figure 1).

Figure 1. **Percentage of Facebook company profiles (FB COM), group pages (FB GROUP), and links (Link) to a Facebook account on hospital websites at T3 (April to July 2011)**



NL = the Netherlands, BE = Belgium, LU = Luxembourg, DE = Germany, AT = Austria, CH = Switzerland, UK = United Kingdom, IR = Ireland, NO = Norway, SE = Sweden, FI = Finland, DK = Denmark.

Blogs

Blogs were found in 7 of the 12 countries, ranging from 1% (n=1) in Germany to 9% (n=2) in Sweden (Table 4). We found blogs less frequently than the other types of social media. The percentages of blogs differed significantly between countries ($\chi 2$ 11 = 28.5, P = .003).

Table 3. Social media usage (T1–T3)[a] in 12 Western European countries (YouTube and Twitter)

Country[b]	YouTube, n (%)			P value		Twitter, n (%)			P value	
	T1	T2	T3	T1 vs T2 vs T3[c]	T1 vs T3[d]	T1	T2	T3	T1 vs T2 vs T3[c]	T1 vs T3[d]
NL (n=88)	9 (10%)	23 (26%)	33 (38%)	<.001	<.001	4 (5%)	27 (31%)	49 (56%)	<.001	<.001
BE (n=91)	1 (1%)	4 (4%)	5 (5%)	.04	.14	0	2 (2%)	6 (7%)	.009	.03
LU (n=6)	0.0	1 (17%)	1 (17%)	.37	1	0	0	0	ND	ND
DE (n=347)	3 (1%)	20 (6%)	52 (15%)	<.001	<.000	2 (1%)	9 (3%)	23 (7%)	<.001	<.001
AT (n=25)	0	3 (12%)	3 (12%)	.05	.25	0	0	0	ND	ND
CH (n=41)	0	2 (5%)	5 (12%	.02	.06	0	1 (2%)	1 (2%)	.37	1
UK (n=175)	6 (3%)	37 (21%)	62 (35%)	<.001	<.001	4 (2%)	42 (24%)	68 (39%)	<.001	<.001
IR (n=28)	0	0	0	ND	ND	0	0	1 (4%)	.37	1
NO (n=17)	0.0	2 (12%)	3 (18%)	.1	1	0	2 (12%)	8 (47%)	.002	.008
SE (n=22)	0	5 (23%)	5 (23%)	.007	1	0	2 (9%)	2 (9%)	.14	.5
FI (n=9)	0	0	0	ND	ND	0	0	0	ND	ND
DK (n=24)	0.0	2 (8%)	3 (13%)	.1	.25	0	0	0	ND	ND
All (n=873)	19 (2%)	99 (11%)	172 (19.7%)	<.001	<.001	10 (1%)	85 (10%)	158 (18.1%)	<.001	<.001

[a] T1 = April to August 2009, T2 = August to December 2010, T3 = April to July 2011.

[b] NL = the Netherlands, BE = Belgium, LU = Luxembourg, DE = Germany, AT = Austria, CH = Switzerland, UK = United Kingdom, IR = Ireland, NO = Norway, SE = Sweden, FI = Finland, DK = Denmark.

[c] Cochran Q test (df = 2).

[d] McNemar test (df = 2).

ND = No data.

Table 4. Social media usage (T1–T3)[a] in 12 Western European countries (Facebook, blogs, and LinkedIn)

Country[b]	Facebook, n (%)			P value	Blog, n (%)			P value		LinkedIn, n (%)			P value
	T1	T2	T3	T2 vs T3[c]	T1	T2	T3	T1 vs T2 vs T3[d]	T1 vs T3[c]	T1	T2	T3	T2 vs T3[c]
NL (n=88)	ND	0	13 (15%)	<.001	2 (2%)	5 (6%)	4 (5%)	.1	.5	ND	48 (55%)	71 (81%)	<.001
BE (n=91)	ND	20 (22%)	62 (68%)	<.001	2 (2%)	2 (2%)	2 (2%)	1	1	ND	20 (22%)	41 (45%)	<.001
LU (n=6)	ND	0	3 (50%)	.25	0	0	0	ND	ND	ND	0	2 (33%)	.5
DE (n=347)	ND	26 (8%)	232 (66.9%)	<.001	0	0	1 (1%)	.37	1	ND	6 (2%)	10 (3%)	.22
AT (n=25)	ND	1 (4%)	21 (84%)	<.001	0	0	0	ND	ND	ND	1 (4%)	3 (12%)	.5
CH (n=41)	ND	4 (10%)	15 (37%)	.001	0	0	0	ND	ND	ND	5 (12%)	9 (22%)	.13
UK (n=175)	ND	31 (18%)	163 (93.1%)	<.001	0	10 (6%)	12 (7%)	<.001	<.001	ND	71 (41%)	97 (55%)	<.001
IR (n=28)	ND	0	23 (82%)	<.001	0	0	0	ND	ND	ND	0	3 (11%)	.25
NO (n=17)	ND	2 (12%)	15 (88%)	<.001	0	0	1 (6%)	.37	1	ND	8 (47%)	13 (76%)	.06
SE (n=22)	ND	0	10 (45%)	<.001	3 (14%)	3 (14%)	2 (9%)	.37	1	ND	15 (68%)	17 (77%)	.5
FI (n=9)	ND	0.0	7 (78%)	.02	0	0	0	ND	ND	ND	0	1 (11%)	1
DK (n=24)	ND	1 (4%)	21 (88%)	<.001	0	0	1 (4%)	.37	1	ND	5 (21%)	11 (46%)	.03
All (n=873)	ND	85 (10%)	585 (67.0%)	<.001	7 (1%)	20 (2%)	23 (3%)	<.001	<.001	ND	179 (20.5%)	278 (31.8%)	<.001

[a] T1 = April to August 2009, T2 = August to December 2010, T3 = April to July 2011.

[b] NL = the Netherlands, BE = Belgium, LU = Luxembourg, DE = Germany, AT = Austria, CH = Switzerland, UK = United Kingdom, IR = Ireland, NO = Norway, SE = Sweden, FI = Finland, DK = Denmark.

[c] McNemar test (df = 2).

[d] Cochran Q test (df = 2).

ND = No data

Table 5. YouTube videos, views, and Twitter followers at T2 and T3[a]

Country[b]	YouTube videos per account, median (IQR)		P value	YouTube views per account, median (IQR)		P value	Twitter followers per account, median (IQR)		P value
	T2	T3	T2 vs T3[c]	T2	T3	T2 vs T3[c]	T2	T3	T2 vs T3[c]
NL (n=88)	5 (2-20)	9 (5-26)	.03	839 (221-1721)	4828 (976-12,022)	<.001	119 (48-235)	336 (150-748)	<.001
BE (n=91)	3 (2-3)	7 (3-9)	.18	241 (145-241)	6648 (3332-13,241)	.04	175	127 (41-232)	ND[e]
LU (n=6)	5 (a)	4 (a)	ND	141	244	ND	0	0	ND
DE (n=347)	2 (2-17)	6 (3-19)	01	1809 (737–-7,823)	1920 (382-11,366)	.001	51 (27-76)	90 (30-309)	.18
AT (n=25)	20 (10-22)	32 (18-58)	.11	10,930 (5465-12,755)	26,251 (19,855-29,692)	.18	0	0	ND
CH (n=41)	2 (2-3)	6 (3-16)	1	3 (a)	3717 (2003-3853)	ND	19	63	ND
UK (n=175)	5 (2-8)	7 (4-16)	.004	256 (13-1436)	2372 (880-7313)	<.0001	311 (135-625)	464 (145-1019)	<.001
IR (n=28)	0	0	ND	0	0	ND	0	44 (a)	ND
NO (n=17)	7 (5-8)	4 (3-8)	.32	2962 (2700-223)	5250 (5200-7082)	.18	57 (30-83)	200 (65-370)	.18
SE (n=22)	13 (7-16)	12 (4-12)	.13	560 (458-7199)	3146 (1892-12,029)	.35	84 (75-92)	142 (116-169)	.18
FI (n=9)	0	0	ND	0	0	ND	0	0	ND
DK (n=24)	1 (1-2)	3 (3-3)	ND	101 (51-152)	120.0 (71-168)	ND	0	0	ND
All (n=873)	4 (2-13)	7 (3-16)	<.001	575 (190-2444)	3074 (724-10,110)	<.001	204 (74-579)	271 (85-724)	<.001

[a] T2 = August to December 2010, T3 = April to July 2011.

[b] NL = the Netherlands, BE = Belgium, LU = Luxembourg, DE = Germany, AT = Austria, CH = Switzerland, UK = United Kingdom, IR = Ireland, NO = Norway, SE = Sweden, FI = Finland, DK = Denmark.

[c] Wilcoxon signed rank test.

IQR = Interquartile range

ND = No data

LinkedIn

We measured LinkedIn during two periods (T2 and T3). We found significantly increased usage in 4 countries. At T3, the percentage of LinkedIn accounts ranged from 3% (n=10) in Germany to 81% (n=71) in the Netherlands (Table 4), and the percentages were significantly different ($\chi 2$ 11 = 336.4, P < .001). Of all 873 hospitals, we found 1 hospital with a link to their LinkedIn profile on their website.

Discussion

In this longitudinal study we explored the use of social media by 873 hospitals in 12 Western European countries. The use of social media increased in all of the countries, especially YouTube (from 2% to 19.7%), LinkedIn (20.5% to 31.8%), and Facebook (10% to 67.0%). This increased use of social media has been confirmed by other studies [14]. Interestingly, the use of Twitter, Facebook, and YouTube in Europe appeared to be higher than in the United States [15].

There are notable differences between the 12 countries. The use of Twitter was especially popular in the United Kingdom, the Netherlands, and Norway. At the third measurement, almost half of all hospitals in the Netherlands and in Norway were on Twitter. YouTube was used by 35% of the hospitals in the United Kingdom and 38% in the Netherlands, whereas the use of YouTube varied from 0% to 23% in all other countries. There are several possible reasons for the differences between countries that we found. First, the use of social media could be related to the Internet penetration in a specific country. However, the differences in broadband penetration in Europe are small [21]. Second, there may be an influence of local or country-specific social media. An example is Hyves, which was, until recently, the most popular social network in the Netherlands, with more than 11 million members [22]. This could explain why Facebook was less popular in the Netherlands than in other countries. It is difficult to predict the popularity or influence of other social media. Online sources show that Facebook, when Hyves is excluded, was the most popular social media network in all other countries during the research period [19,20].

The activity of hospitals on social media increased during the research period, as the number of videos and viewers of YouTube channels, and of Twitter followers increased. Furthermore, the increased usage of LinkedIn was notable in the Netherlands and the United Kingdom at the third measurement. Hospitals in these countries seem to be aware of the benefits of recruiting personnel that LinkedIn offers. However, the observation that only 5% (n=48) of all 873 hospitals had a link to their YouTube channel and 10% (n=90) had a link to their Twitter feed on their website indicates that hospitals are not using the full potential of all types of social media yet. Based on this study, we cannot say anything about the content of videos, tweets, and messages. However, our data show that an ever-increasing number of users are watching the videos and reading the tweets.

Since Western European hospitals have become aware of social media and increasingly use it, we foresee great opportunities to improve health care and to stimulate participatory health care. Various studies have described improvements that social media could offer to health care, such as greater transparency, openness, and communication, and improved patient support and knowledge translation [4,10]. Therefore, research should be focused on describing best practices, which may help speed up implementation of social media. Furthermore, it would be worthwhile to identify for what purposes hospitals use social media and to what extent social media improve participatory health care. For a complete overview, future research should also focus on the challenges and risks of using social media, such as legal constraints, fraud, and budget constraints. These topics are also important research subjects in the light of the discussion about desirability of social media usage by health care professionals.

Our study has some limitations that need to be discussed. In a few cases, we experienced difficulties determining whether a social network was official (was initiated and maintained by the hospital itself). However, we gave hospitals the opportunity to correct their data. Another aspect is the differences between health care systems in the included countries. We found that in a few countries, some hospital organizations included more than 1 hospital. Since we counted these organizations as 1 hospital, our data do not reflect the results of individual hospitals in every country. Another aspect is that we measured Facebook and LinkedIn only at T2 and T3. It would have been interesting to see the results for T1. However, at the start of the project, we were not aware of hospitals using Facebook or LinkedIn. Since Facebook and LinkedIn became increasingly popular in 2009 and 2010, we decided to include them in the search we conducted in this study.

Awareness and use of social media is growing in Western European hospitals. Social media usage differs significantly between countries. Except for the Netherlands and the United Kingdom, the group of hospitals that are using social media remains small. Usage of LinkedIn for recruitment of personnel shows that hospitals are aware of the potential of social media. Future research is needed to investigate how social media lead to improved health care.

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4

Internet and Social Media For Health-Related Information and Communication in Health Care: Preferences of the Dutch General Population

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Abstract

Background: Health care is increasingly featured by the use of Web 2.0 communication and collaborative technologies that are reshaping the way patients and professionals interact. These technologies or tools can be used for a variety of purposes: to instantly debate issues, discover news, analyze research, network with peers, crowd-source information, seek support, and provide advice. Not all tools are implemented successfully; in many cases, the nonusage attrition rates are high. Little is known about the preferences of the Dutch general population regarding the use of the Internet and social media in health care.

Objective: To determine the preferences of the general population in the Netherlands regarding the use of the Internet and social media in health care.

Methods: A cross-sectional survey was disseminated via a popular Dutch online social network. Respondents were asked where they searched for health-related information, how they qualified the value of different sources and their preferences regarding online communication with health care providers. Results were weighed for the Dutch population based on gender, age, and level of education using official statistics. Numbers and percentages or means and standard deviations were presented for different subgroups. One-way ANOVA was used to test for statistical differences.

Results: The survey was completed by 635 respondents. The Internet was found to be the number one source for health-related information (82.7%), closely followed by information provided by health care professionals (71.1%). Approximately one-third (32.3%) of the Dutch population search for ratings of health care providers. The most popular information topics were side effects of medication (62.5%) and symptoms (59.7%). Approximately one-quarter of the Dutch population prefer to communicate with a health care provider via social media (25.4%) and 21.2% would like to communicate via a webcam.

Conclusion: The Internet is the main source of health-related information for the Dutch population. One in 4 persons wants to communicate with their physician via social media channels and it is expected that this number will further increase. Health care providers should explore new ways of communicating online and should facilitate ways for patients to connect with them. Future research should aim at comparing different patient groups and diseases, describing best practices, and determining cost- effectiveness.

Introduction

Health care is increasingly featured by the use of Web 2.0 communication and collaborative technologies that are reshaping the way patients and professionals interact [1]. This process, in which Web 2.0 tools are used in health care, is part of Health 2.0 (also known as Medicine 2.0) [2], an important fundament of which is the use of social media [3]. Kaplan and Haenlein [4] define social media as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0 and that allow the creation and exchange of user-generated content". Well-known examples are YouTube, Facebook, and Twitter. These can be used for a variety of purposes: to instantly debate issues, discover news, analyze research, network with peers, crowd-source information, seek support, and provide advice [5]. Research shows that larger health care organizations, such as hospitals, are increasingly using social media [6,7]. In many cases, the ultimate goal is to make health care better or more cost-efficient [8].

Since the arrival of social media interventions for health-related purposes, it has become clear that not all of these interventions are actually successful. Although no studies exist that have investigated this problem for social media, eHealth literature, which overlaps with social media because both involve technology, could provide some insight into this problem. It is known that interventions are often not successful and/or the attrition rates may be high [9-11]. Several explanations for unsuccessful use have been described: (1) technology features (e.g. imperfections of the technology), (2) inadequate reimbursement or legislation issues, (3) poor coordination and introduction of tools and (4) personal characteristics of the intended use [9,12]. Personal characteristics seem to be particularly relevant because they concern the end-users of the tool. Examples of such characteristics, which are known to significantly influence use, are negative attitude toward technology, the extent to which a person feels he has the skills and expertise to be a competent caregiver, and age [9]. Therefore, determining the preferences or needs of potential users of tools is an important step in implementation [12-14]. Although studies have assessed patients' preferences regarding the Internet in health care, e.g. the preferred language on websites [15], the preferences of a Web-based intervention [16], preferences regarding social media and asthma patients [17], or the needs of elderly patients regarding eHealth [18], less is known about the preferences or needs of consumers or the general public, especially regarding social media. A survey showed that 32% of all respondents (US adults) had used social media for health care purposes at one time or another [19]. Further insights, however, are lacking. Questions that arise in this context are: Where do people obtain online health-related information? Where do they connect with peers? Are they willing to ask their doctor questions using a webcam? And are there differences between different groups of the population (e.g., by gender, age, or education)?

For that reason, we sought to determine the preferences of the general population in the Netherlands regarding the use of the Internet and social media in health care, by using an online survey that was disseminated via an online social network.

Methods

Design, setting and population

A cross-sectional survey was disseminated via a popular Dutch online social network. Hyves was selected as the social network for dissemination of the survey. This social network has long been the most popular Dutch online social network, with 9.7 million members of all ages [20,21], comprising more than half of the Dutch population [22]. Hyves can be used to create a personal profile and connect with friends. Furthermore, users can like pages or create groups. Between October 4 and November 4, 2011, Hyves members aged at least 15 years were randomly invited through Hyves' internal message system. There were no restrictions regarding sex, race, or income. The messages contained a description of the project (in Dutch) and a link to the survey.

Questionnaire development and content

Overview

A first draft of the questionnaire was created by TB and subsequently discussed with LE and LS. This version was shared with 3 experts: a social media expert, a researcher (SB), and an epidemiologist. After discussion, consensus was reached and the survey was finalized and uploaded to the online system. The questionnaire consisted of 17 multiple-choice questions divided over 3 sections: (1) sociodemographic, (2) health-related information and Internet, and (3) respondents' preferences regarding communication in health care. All questions were written in Dutch. The final survey (English version) is available in Appendix 1.

Sociodemographic section

The sociodemographic section contained questions about age, gender, and level of education.

Health-related information and Internet

In the health-related information and Internet section, respondents were asked where they searched for health-related information and how they qualified the value of different sources. The topics were:

1. Sources of health-related information;
2. Type of online information that is searched for;
3. Frequency of health-related searches; and
4. Perceived reliability of different sources.

Respondents' preferences regarding communication in health care

In the preferences section, preferences regarding communication in health care were acknowledged.

Response

A total of 4232 people selected the link to the online survey, of which 679 filled out the survey. After excluding incomplete surveys or surveys completed by respondents under 15 years (n=44), 635 cases were analyzed. The mean response time was 6.13 minutes (SD 2.95).

Statistical analysis

The data were downloaded from the online system and analyzed in SPSS version 20 (IBM Corp, Armonk, NY, USA). We used descriptive statistics to examine the proportions for different age, gender, and education groups. Proportions for age were summarized in 6 age groups: 15-24, 25-34, 35-44, 45-54, 55-64, and 65 or older.

Answers regarding health-related information and the Internet as well as preferences of communication in health care were extrapolated to the Dutch population based on gender, age, and level of education. We decided to create 2 age groups based on different generations described in the literature [23]. The first group consisted of people aged 15-34. This group has been described as the Generation Y and consists of people who grew up with the Internet. The second age group consisted of persons aged 35 or older, including the Generation X and the so-called baby-boomers. Two levels of education were recognized. The first group consisted of people with no education or lower education, whereas the second group consisted of moderately or highly educated people.

For each stratum (combination of gender, age, and educational level), the response within the survey was estimated. The response of the stratum was then weighted by the relative frequency of that stratum within the Dutch population of 2011, acquired via Statistics Netherlands (Centraal Bureau voor de Statistiek, CBS) [22]. CBS is a Dutch governmental institution and part of the Dutch Ministry of Economic Affairs that is responsible for gathering and publishing official statistics about the Netherlands. CBS statistics are only published if they are valid and if the overall quality can be guaranteed. The following example shows how we weighed data: if the percentage of young males and old males saying yes was 40% and 60%, respectively, then this would result in a mean of 50% in our sample. Given that young and old males (from CBS statistics) form 0.3 and 0.7 of the Dutch male population, respectively, the percentage of males who would say yes in the Dutch population was estimated to be (0.3x40%) + (0.7x60%)= 54%.

We present numbers and percentages or means and standard deviations. To properly test differences between groups in the response (e.g., male vs female) extrapolated to the Dutch population, we needed to take into account that (1) the precision of the estimated response percentages in strata is determined by the size of the strata in the survey, and (2) these response percentages are weighted by the relative frequency of those strata in the Dutch population. To accomplish this, we used the SPSS procedure 1-way ANOVA to (1) estimate the response percentages with their corresponding precision from the survey, and (2) perform the weighting by

specifying the relative frequencies in contrast tests. Because the size of the strata was reasonably large (> 25) and the response within strata was not close to zero or 100%, the ANOVA means and standard errors were considered a good approximation of the response percentages of the strata. P values < .05 were considered statistically significant.

Results

Sociodemographic

In total, 635 respondents completed the survey, consisting of 95 (15.0%) men and 540 (85.0%) women. Table 1 shows the age distribution for all respondents in 10-year age ranges. In all, 181 respondents (28.5%) had no education or low education and 454 (71.5%) were moderately or highly educated.

Table 1. Survey respondents (n=635)

	n (%)
Gender	
Male	95 (15.0)
Female	540 (85.0)
Age	
15-24	74 (11.7)
25-34	90 (14.2)
35-44	144 (22.7)
45-54	172 (27.1)
55-64	129 (20.3)
65 or older	26 (4.1)
Education	
No/Lower education	181 (28.5)
Moderate or high education	454 (71.5)

Sources of health-related information

Table 2 shows the popularity of different sources of health-related information estimated for the Dutch population. Internet and physicians were found to be the most popular sources (82.7% and 71.1% respectively). Family and friends were mentioned by 20.5% of the Dutch population. People aged ≤ 34 years consulted their family and friends significantly more often than people older than 34 years (38.1% vs. 13.5%, 1-way ANOVA, contrast test t_{627} = 3.52, P < .001). Higher educated people also consulted their family and friends more often (12.5% for lower educated people vs 24.7% for higher educated persons, 1-way ANOVA, contrast test t_{627} = -2.05, P = .04). Patient information leaflets or books were the least popular information source (14.6%).

Table 2. Sources for health-related information

	Total, %[a]	Group 1, %[b]	Group 2, %[b]	t_{627}	P
Gender					
Internet	82.7	82.8	82.6	.11	.91
Physician	71.1	66.2	74.9	-1.45	.15
Family/friends	20.5	19.7	21.2	-.29	.78
Patient information (leaflets, books)	14.6	11.6	17.5	-1.19	.23
Age					
Internet	82.7	87.4	74.0	.99	.32
Physician	71.1	63.8	74.0	-1.30	.19
Family/friends	20.5	38.1	13.5	3.52	< 0.001
Patient information (leaflets, books)	14.6	15.0	14.5	.04	.97
Education					
Internet	82.7	78.0	85.2	-1.25	.21
Physician	71.1	69.8	71.8	-.34	.74
Family/friends	20.5	12.5	24.7	-2.05	.04
Patient information leaflets, books	14.6	9.3	17.5	-1.43	.15

[a] Estimations for Dutch population (%) based on the study sample of 635 respondents. Note that these estimates are weighted sums of the cell response percentages; therefore, n's cannot be provided (see Methods) for these percentages.

[b] For gender, group 1=male, group 2=female; for age, group 1=≤34 years, group 2=age>34 years; for education, group 1=no or low education, group 2=moderate or high education

Type of online information searched for

The most popular information topics that were searched online (Table 3) were side effects of medication and symptoms (62.5% and 59.7%, respectively). People aged 35 years or older searched significantly more often for information on side effects than people younger than 35 years (68.7% vs 46.8%, 1-way ANOVA, contrast test t_{627} = -2.63, P = .01). People younger than 35 years searched more often for symptoms than persons aged 35 or above (76.1% vs 53.2%, 1-way ANOVA, contrast test t_{627} = 2.65, P = .01). Furthermore, women indicated that they searched more often for information on diagnoses than men (58.8% vs 31.5%, 1-way ANOVA, contrast test t_{627} = -4.13, P < .001).

Table 3. Type of health-related information searched for online

	Total, %[a]	Group 1, %[b]	Group 2, %[b]	t_{627}	P
Gender					
Side effects medication	62.5	58.2	66.9	-1.17	.24
Symptoms	59.7	58.7	60.5	-.13	.90
Diagnoses	45.6	31.5	58.8	-4.13	< .001
Patients' experiences	41.7	37.1	46.0	-1.27	.20
Health care insurance	41.6	38.0	44.9	-.99	.32
Therapy	39.3	34.6	43.6	-1.35	.18
My hospital	35.4	38.9	32.1	1.2	.23
Ratings of health care providers	32.3	36.6	28.3	1.4	.16
Health problems	14.8	13.8	15.7	-.20	.83
Manufacturers of medication	8.9	10.7	7.2	.98	.33
Second opinion	6.8	5.8	7.8	-.65	.52

	Total, %[a]	Group 1, %[b]	Group 2, %[b]	t_{627}	P
Age					
Side effects medication	62.5	46.8	68.7	-2.63	.01
Symptoms	59.7	76.1	53.2	2.65	.01
Diagnoses	45.6	44.4	46.1	-.21	.83
Patients' experiences	41.7	35.0	44.3	-1.1	.27
Health care Insurance	41.6	34.6	44.3	-1.11	.27
Therapy	39.3	30.3	42.8	-1.43	.15
My hospital	35.4	32.2	36.7	-.55	.58
Ratings of health care providers	32.3	30.2	33.2	-.37	.71
Health problems	14.8	10.6	16.4	-.95	.34
Manufacturers of medication	8.9	6.2	9.7	-.65	.52
Second opinion	6.8	10.0	5.6	1.01	.31
Education					
Side effects medication	62.5	58.4	64.7	-.86	.39
Symptoms	59.7	55.2	62.0	-.88	.38
Diagnoses	45.6	40.9	48.1	-.98	.33
Patients' experiences	41.7	36.4	44.6	-1.08	.28
Health care Insurance	41.6	31.7	46.9	-1.94	.05
Therapy	39.3	33.6	42.3	-1.08	.28
My hospital	35.4	29.0	38.8	-1.34	.18
Ratings of health care providers	32.3	31.1	31.9	.17	.86
Health problems	14.8	12.8	15.9	-.54	.59
Manufacturers of medication	8.9	5.6	10.7	-1.25	.21
Second opinion	6.8	4.3	8.2	-1.03	.30

[a] Estimations for Dutch population (%) based on the study sample of 635 respondents. Note that these estimates are weighted sums of the cell response percentages; therefore, n's cannot be provided (see Methods) for these percentages.

[b] For gender, group 1=male, group 2=female; for age, group 1=≤34 years, group 2=age>34 years; for education, group 1=no or low education, group 2=moderate or high education

Frequency of health-related searches

We determined the frequency of online health-related searches extrapolated to the Dutch population. In all, 92% indicated that they searched for health-related information at least once a year and 24.4% searched for health-related information at least every month.

Table 4 shows the search behavior of Dutch people before consulting a physician (e.g. general practitioner or specialist). In all, 42.3% indicated that they sometimes searched online for health-related information and 18.4% indicated that they never searched online for information before visiting a physician. Table 4 also shows the search behavior after visiting a physician (general practitioner or specialist). In all, 44.4% indicated that they sometimes searched online for health-related information after visiting their physician and 17.0% indicated that they never searched online for information after having visited their physician.

Table 4. Online searches for health-related information before and after visiting physician (general practitioner or specialist)

Moment of search (before/ after)	Total[a]	Gender				Age				Education			
		Male	Female	t_{627}	P	≤ 34	> 34	t_{627}	P	No/ Low	Mod/ high	t_{627}	P
Search before,%				-1.69	.09			3.34	.001			1.65	.10
Very Often	4.3	4.1	4.5			11.0	1.7			2.9	5.1		
Often	18.3	18.4	18.2			29.0	14.0			25.4	14.5		
Sometimes	42.3	34.8	49.3			39.9	43.3			50.4	37.9		
Rarely	16.7	18.5	15.0			9.3	19.6			8.7	21.0		
Never	18.4	24.1	13.1			10.9	21.4			12.6	21.6		
Search after,%				-3.52	<.001			-0.88	.38			0.48	.63
Very Often	2.5	1.5	3.5			3.9	2.0			2.7	2.4		
Often	14.8	10.9	18.5			12.8	15.6			10.8	17.0		
Sometimes	44.4	36.6	51.8			36.6	47.5			53.3	39.6		
Rarely	21.2	29.5	13.4			27.3	18.7			22.1	20.7		
Never	17.0	21.5	12.8			19.4	16.1			11.1	20.2		

[a] Estimations for Dutch population (%) based on the study sample of 635 respondents. Note that these estimates are weighted sums of the cell response percentages; therefore, n's cannot be provided (see Methods) for these percentages.

4

Perceived reliability of sources and other preferences

Table 5 shows the perceived reliability of sources of health-related information. On a scale from 1 (very unreliable) to 10 (very reliable), people rated their physician and their personal opinion as most reliable (7.3 and 7.5, respectively). Internet and family/friends scored 6.0 and 5.9 on the scale of reliability, respectively. The least reliable source is information retrieved via social media: 3.8 of 10. Family/friends were found to be more reliable by younger persons than older ones (6.7 vs 5.6, 1-way ANOVA, contrast test t_{627} = 3.29, P = .001). Furthermore, higher educated people rated their personal opinion as more reliable than lower educated persons (7.7 vs 7.0, 1-way ANOVA, contrast test t_{627} = -2.35, P = .02).

Table 5. Perceived reliability of sources for health-related information

	Total, mean[a]	Group 1, mean[b]	Group 2, mean[b]	t_{627}	P
Gender					
Self	7.5	7.4	7.5	-.42	.67
Physician	7.3	7.4	7.2	.87	.38
Internet	6.0	6.0	6.0	.18	.86
Friends/family	5.9	6.0	5.8	.98	.33
Social media	3.8	3.7	3.8	.04	.97
Age					
Self	7.5	7.8	7.3	1.47	.14
Physician	7.3	7.6	7.2	1.12	.26
Internet	6.0	6.2	5.9	.97	.33
Friends/family	5.9	6.7	5.6	3.29	.001
Social media	3.8	3.2	4.0	-2.03	.04

	Total, mean[a]	Group 1, mean[b]	Group 2, mean[b]	t_{627}	P
Education					
Self	7.5	7.0	7.7	-2.35	.02
Physician	7.3	7.1	7.4	-0.77	.44
Internet	6.0	6.0	6.0	-.31	.76
Friends/family	5.9	6.1	5.8	1.07	.29
Social media	3.8	3.6	3.8	-.69	.49

[a] Estimations for Dutch population (on a scale from 1 to 10; 1=very unreliable, 10=very reliable), based on the study sample of 635 respondents. Note that these estimates are weighted sums of the cell response percentages; therefore, n's cannot be provided (see Methods) for these percentages.

[b] For gender, group 1=male, group 2=female; for age, group 1=≤34 years, group 2=age>34 years; for education, group 1=no or low education, group 2=moderate or high education

Respondents' preferences regarding communication in health care

Table 6 shows to which extent Dutch people would like to communicate using social media or webcams. In all, 25.4% prefer to communicate with their health care provider via social media. Furthermore, 21.2% would like to communicate with their health care providers via a webcam. No statistical differences were found between subgroups.

Table 6. Preferences for communication in health care

	Total, %[a]	Group 1, %[b]	Group 2, %[b]	T (df)	P
Gender					
Would like to ask questions to health care provider via Social Media[a]	25.4	27.4	23.7	.64 (573)	.52
Would like to communicate with health care provider via Webcam[c]	21.2	25.2	17.5	1.41 (563)	.16
Age					
Would like to ask questions to health care provider via Social Media[a]	25.4	19.6	27.8	-1.04 (573)	.30
Would like to communicate with health care provider via Webcam[c]	21.2	11.7	25.0	-1.84 (563)	.07
Education					
Would like to ask questions to health care provider via Social Media[a]	25.4	23.6	26.6	-.43 (573)	.67
Would like to communicate with health care provider via Webcam[c]	21.2	18.0	22.9	-.76 (563)	.45

[a] Estimations for the Dutch population (%) based on survey sample of 581 (54 respondents excluded because they selected: no opinion). Note that these estimates are weighted sums of the cell response percentages; therefore, n's cannot be provided (see Methods) for these percentages.

[b] For gender, group 1=male, group 2=female; for age, group 1=≤34 years, group 2=age>34 years; for education, group 1=no or low education, group 2=moderate or high education

[c] Estimations for the Dutch population (%) based on survey sample of 571 (64 respondents excluded because they selected: no opinion). Note that these estimates are weighted sums of the cell response percentages; therefore, n's cannot be provided (see Methods) for these percentages.

Discussion

Principal findings

As far as we are aware, ours is the first study to investigate online search behavior and preferences regarding the use of social media in health care in the Netherlands. Making use of official statistics, survey results for 635 respondents were successfully extrapolated to the general Dutch population.

The Internet was found to be the number one source for health-related information (82.7%), closely followed by information provided by health care professionals (71.1%). For all groups, the least frequently used source of information was hard copy information, such as leaflets/books. This is higher than AlGhamdi et al. [24] found in a survey that included the same age population. They showed that 58.4% of all respondents searched online for health-related information and that health care professionals were the primary source of health-related information. Our findings correspond with a study performed in Brasil, which found that the Internet was the primary source of health-related information for 86% of all respondents [25]. Similar results were also found in a study involving patients suffering from a chronic disease. Approximately 90% of the respondents that searched for additional disease-related information indicated that they used the Internet [26]. However, the same study showed that 55% of all respondents used information leaflets as a source of information versus 14.5% in the present study. This difference can be explained by differences in the study population: our study included any individual instead of patients with a chronic condition only. Another explanation could be that there are differences in broadband penetration between the 2 countries (United States 56.1% vs Netherlands 92.9%) [27]. Health care providers should recognize that a large majority of the Dutch population use online sources for health-related information. Therefore, they should focus on providing high-quality patient information via online channels.

The Dutch population searches online for several health-related topics. In all, 9 of 10 persons indicated that they searched for health-related information at least once a year and 1 in 4 searched for health-related information at least every month. Three topics that were most frequently mentioned (≥ 45.6%) are side effects of medication, symptoms and diagnoses. People aged 35 years or older searched more often for side effects of medication than their younger counterparts did. This is probably because of a higher consumption of medication by older generations.

Approximately one-third (32.3%) of the Dutch population searches for ratings of health care providers. This is slightly more than was found in a recent report about online health in the United States [28]. This report shows that 10% to 20% of the US population searches for physician ratings, reviews, and rankings. We foresee that more people will search for ratings in the near future, as a rapid rise of health care-related rating websites created by the government, patients' organizations and other parties can be witnessed [29]. An example of such a rating site is

Zorgkaart Nederland [30], a website containing a database with information about all health care providers in the Netherlands. Anyone can rate their health care provider and add their comments or experiences. Currently, it contains information about 112,832 health care providers. The observation that an increasing number of people share their experiences online is supported by our finding that the Dutch population rates their own opinion as important. Interestingly, patients' ratings are significantly associated with official patient surveys about the quality of care [31]. This may be an important finding for future researchers and/or governmental parties (e.g. health care inspection) because it could help them in determining high-quality care providers, but also in detecting harmful or unwanted situations.

Approximately 1 in 4 persons would like to use social media to consult their physician and 1 in 5 persons would like to communicate with their physician using a webcam. With the growing number of mobile devices, such as smartphones and tablets, we expect the number of people wanting to communicate via social media channels or via webcams to increase as well particularly because usability issues for mobile devices are becoming less relevant [32] and there are tools available that use safe connections that protect data and respect the privacy of users, such as Facetalk [33]. Therefore, future researchers should focus on describing best practices for online patient-physician communication and determine the cost-effectiveness. It would also be interesting to study the extent to which face-to-face technology and social media support patient empowerment, which is a term used to describe the process in which consumers are taking an active role in their care process and where the traditional doctor-patient relationship is disappearing [34].

Limitations

Our study has some limitations that need to be discussed. Although using a social network was helpful in reaching a large group of people very quickly and at relatively low costs, there are some relevant downsides. The online system that sent invitations to Hyves' members randomly did not allow us to register the number of invitations sent. Furthermore, we were not able to distinguish between people who had actually seen the request but had refused to fill in the survey or people who had not seen the request at all (e.g. invitation ended up in spam or junkmail folder). As a result, it was impossible to determine exact response percentages. Although we know that people of all genders, ages, and education levels were active on Hyves at the time of the study and that we corrected for overrepresented or underrepresented groups by using official statistics, it is important to consider that all respondents were recruited via an online social network. As a result, we may have missed a specific subgroup of the Dutch population consisting of people without access to the Internet. However, we believe this group to be small because 92.9% of the Dutch population has Internet access [27]. In relation to the survey, it is important to consider that it did not include questions about diseases and use of medication by respondents, which made it impossible to distinguish between ill and healthy respondents. Realizing that ill patients may have other preferences, future surveys should include questions on this matter. Because the present

survey was focused on types of information (e.g. social media, Internet, books) future studies should aim to further specify this. For example, they should study which types of social media are used, which search engines are used to search for information, and how consumers rate the reliability of different social media networks or websites.

Conclusion

Internet is the main source of health-related information for the Dutch population. One in 4 persons would communicate with their physician via social media channels and it is expected that this number will further increase. Therefore, health care providers should explore new ways of communicating online and should facilitate ways for patients to connect with them. Future research should aim at comparing different patient groups and diseases, describing best practices, and determining cost-effectiveness.

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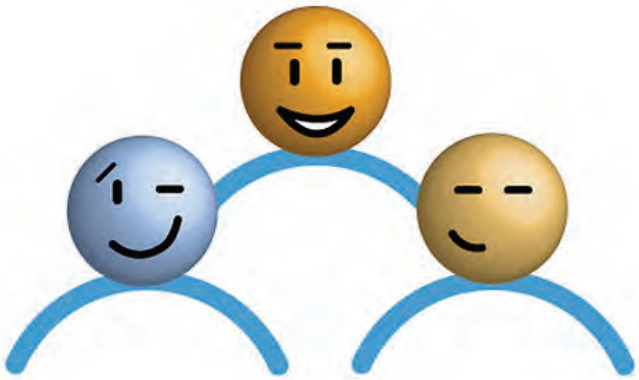
Appendix 1

Survey Hyves Version 1 (English version)



Survey on the use of the Internet and social media for health-related purposes

Hyves

UMC St Radboud

Radboud REshape & Innovation Center

Survey Hyves Version 1 (English version)

Dear Hyver,

The Radboud REshape & Innovation Center is interested in the extent to which people use the Internet and social media in relation to their health and for health care. If we could achieve a better insight into their preferences and needs, we will be able to adapt health care to it. By participating in this survey you will not only help us, but also yourself.

This survey contains 17 multiple choice questions and it will take approximately 5 minutes of your time.

Thank you very much for your cooperation!

Survey Hyves Version 1 (English version)

1. Where do you find information about your health? (multiple answers possible)
   - ❑ Internet (computer/smartphone e.d.)
   - ❑ Physician (e.g. GP)
   - ❑ Information leaflets, books
   - ❑ Family, friends, or other acquaintances
   - ❑ Other: [text box]

2. What do you look for on the Internet? (multiple answers possible)
   Information about:
   - ❑ Health care insurance
   - ❑ Second opinion
   - ❑ Medication and/or side effects
   - ❑ Manufacturers of medication (Pharmacy)
   - ❑ My hospital or my physician (e.g. GP)
   - ❑ Other patients' experiences
   - ❑ Specific diagnoses or diseases
   - ❑ Therapy or treatment
   - ❑ Symptoms
   - ❑ Health problems
   - ❑ Other, namely:

3. Have you ever searched for ratings of your hospital or your physician?
   - Yes
   - No

4. How often (on average) do you search for health-related information online?
   - Daily
   - > Weekly
   - > Monthly
   - > Annually
   - Never

Survey Hyves Version 1 (English version)

5. Do you search online **before** visiting your physician (e.g. GP)?
   - Never
   - Rarely
   - Sometimes
   - Often
   - Very Often

6. Do you search online **after** having visited your physician (e.g. GP)?
   - Never
   - Rarely
   - Sometimes
   - Often
   - Very Often

7. How reliable is the information that you find online? [Select on a scale (1-10)]
   Very unreliable 1 2 3 4 5 6 7 8 9 10 Very reliable

How do you perceive the reliability of peoples' advice regarding health-related decisions? [select on a scale 1-10]

Advice from:

8. Your physician (e.g. GP)
   Very unreliable 1 2 3 4 5 6 7 8 9 10 Very reliable

9. Friends or family
   Very unreliable 1 2 3 4 5 6 7 8 9 10 Very reliable

   People on social networks (e.g. Hyves, Facebook)
   Very unreliable 1 2 3 4 5 6 7 8 9 10 Very reliable

   Your own opinion/feeling
   Very unreliable 1 2 3 4 5 6 7 8 9 10 Very reliable

Survey Hyves Version 1 (English version)

10. Would you like to use a social network (e.g. Hyves, Twitter) to get in touch with your physician (e.g. GP) to be able to ask health-related questions? (If preferred, via a secured connection).
    - Yes
    - No
    - No opinion

11. Would you like to get in touch with your physician (e.g. GP) or hospital using a webcam?
    - Yes
    - No
    - No opinion

This is an anonymous survey. To correctly interpret the results, we ask for a little more information:

12. Your age: ….

13. Your gender: ❑ male ❑ female

14. Please select your highest level of education
    - ❑ No education
    - ❑ Lagere school/basisonderwijs (primary education)
    - ❑ LBO, VBO, LTS, LHNO, VMBO (Lower vocational education)
    - ❑ MAVO, VMBO-t, MBO-kort (Lower general secondary education)
    - ❑ MBO, MTS, MEAO (Intermediate vocational education)
    - ❑ HAVO, VWO, Gymnasium (Highschool)
    - ❑ HBO, HEAO, PABO, HTS (Higher vocational education)
    - ❑ Universiteit (Academic level)
    - ❑ Other: …. [please specify]

15. First four numbers of your postal code:…..

Thank you!

5

Wikis and Collaborative Writing Applications in Health Care: A Scoping Review Protocol

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Abstract

Background: The rapid rise in the use of collaborative writing applications (e.g., wikis, Google Documents, and Google Knol) has created the need for a systematic synthesis of the evidence of their impact as knowledge translation (KT) tools in the health care sector and for an inventory of the factors that affect their use. While researchers have conducted systematic reviews on a range of software-based information and communication technologies as well as other social media (e.g., virtual communities of practice, virtual peer-to-peer communities, and electronic support groups), none have reviewed collaborative writing applications in the medical sector.

Objective: The overarching goal of this project is to explore the depth and breadth of evidence for the use of collaborative writing applications in health care. Thus, the purposes of this scoping review will be to (1) map the literature on collaborative writing applications; (2) compare the applications' features; (3) describe the evidence of each application's positive and negative effects as a KT intervention in health care; (4) inventory and describe the barriers and facilitators that affect the applications' use; and (5) produce an action plan and a research agenda.

Methods: A six-stage framework for scoping reviews will be used: (1) identifying the research question; (2) identifying relevant studies within the selected databases (using the EPPI-Reviewer software to classify the studies); (3) selecting studies (an iterative process in which two reviewers search the literature, refine the search strategy, and review articles for inclusion); (4) charting the data (using EPPI-Reviewer's data-charting form); (5) collating, summarizing, and reporting the results (performing a descriptive, numerical, and interpretive synthesis); and (6) consulting knowledge users during three planned meetings. Since this scoping review concerns the use of collaborative writing applications as KT interventions in health care, we will use the Knowledge to Action (KTA) framework to describe and compare the various studies and collaborative writing projects we find. In addition to guiding the use of collaborative writing applications in health care, this scoping review will advance the science of KT by testing tools that could be used to evaluate other social media. We also expect to identify areas that require further systematic reviews and primary research and to produce a highly relevant research agenda that explores and leverages the potential of collaborative writing software.

Conclusions: To date, this is the first study to use the KTA framework to study the role collaborative writing applications in KT, and the first to involve three national and international institutional knowledge users as part of the research process.

Introduction

Collaborative writing applications and their potential impact on global knowledge translation

In both developed and developing countries, vast numbers of health care decision makers – providers, patients, managers, and policy makers – are failing to use research evidence to inform their decisions [1]. According to behavior change theories [2-4], self-efficacy is one of the most important cognitive determinants of behavior. By involving knowledge users in the dissemination of knowledge [5], social media – highly accessible, interactive vehicles of communication – have the potential to increase users' self-efficacy [5-7] and empower users to apply knowledge in practice. Acknowledging this potential and recognizing that social media capitalizes on the free and open access to information, scientists, opinion leaders, and patient advocates have called for more research to determine whether social media can equip decision-making constituencies to improve the delivery of health care [8,9], decrease its cost [5,10], and improve access to knowledge within developing countries [8,11,12].

Collaborative writing applications [13,14] are a category of social media that has enjoyed a surge in popularity in recent years including within the health care sector [5,7,8,13]. Although no two applications are identical, all consist of software that allows users to create online content that anyone can edit or supplement [15]. Thus, Internet users have turned to wikis [16,17] to produce a Wikipedia entry on the Global Plan to Stop Tuberculosis [8]; to Google Knol [18] to exchange research on influenza at the Public Library of Science [19]; and to Google Docs [14,20] to review the literature on emergency medicine [21,22].

While new collaborative writing applications are continually surfacing, wikis are perhaps the most popular. Wikipedia's medical articles are viewed about 150 million times per month and exist in 271 languages [8]. New wikis have appeared in all fields of health care [13,21,23-30], and studies of developed countries found that 70% of junior physicians use Wikipedia in any given week, that 50% to 70% of practicing physicians use it as a source of information in providing care [8,31], and that 35% of pharmacists refer to it for drug information [32]. Patients also use wikis to share their experiences [33] and to find information [8]. The Canadian Agency for Drugs and Technologies in Health (CADTH) is exploring the use of wikis to update knowledge syntheses [34,35] and the United States' National Institutes of Health (NIH) is training its scientists in editing them [36]. In addition, academic institutions like Harvard [37] and Stanford [13] are using wikis to train health care professionals [13,16,38-43]. Wikis have come to exemplify social media's tremendous promise to enable health care professionals, patients, and policy makers to implement evidence-based practice at remarkably low cost [21,22,44-46]. In doing so, they could improve the health of millions of people around the world [8,12].

Knowledge users' needs

Even as decision makers increase their use of wikis and other collaborative writing applications, questions remain about their safety [47,48], their reliability [49-53], their lack of traditional

authorship [54,55], and the legal implications for decision making [56,57]. Researchers also question clinicians' intention to use the applications in their practice [21] and to contribute knowledge collaboratively [8,22]. For these reasons, the International Medical Informatics Association (IMIA), the Association of Faculties of Medicine of Canada (AFMC), and the Federation of Patients and Consumer Organization in the Netherlands (NPCF) have partnered with our research team to conduct a scoping review to determine the extent of published evidence on these questions.

The Canadian Institutes of Health Research (CIHR) define a knowledge user as "an individual who is likely to be able to use the knowledge generated through research to make informed decisions about health policies, programs, and/or practices [58]". A knowledge user includes, but is not limited to, a practitioner, policy maker, educator, decision maker, health care administrator, community leader, or an individual in a health charity, patient group, private sector organization, or media outlet. In knowledge syntheses like this scoping review, CIHR requires that designated knowledge users be actively involved in all aspects. In line with this definition, the designated knowledge users in this project are IMIA, AFMC, and NPFC. These three organizations represent three different groups of stakeholders interested in the findings of this scoping review. They have been involved from the beginning of this project and will play an essential role in the dissemination and implementation of its results.

The world body for health and biomedical informatics is the IMIA [59]. As an "association of associations", the IMIA acts as a bridge between its constituent nationally based informatics associations and its academic and industry members from around the world, and further to all interested organizations and individuals. The IMIA has a seat at the World Health Organization's (WHO) World Health Assembly, which aims to (1) promote informatics in health care and biomedical research; (2) advance international cooperation; (3) stimulate research, development, and education in this domain; and (4) disseminate and exchange information in this domain.

Representing Canada's 17 faculties of medicine, AFMC is the voice of academic medicine in Canada [60]. The member faculties of AFMC graduate over 2300 physicians each year; have 10,148 undergraduate medical students in training and 12,453 postgraduate trainees; and employ 21,687 full- and part-time faculty members. Thus, AFMC is a leading advocate on issues relating to health education, health research, and clinical care. Recently, AFMC has embarked on a series of projects aimed at meeting changing societal needs with innovative educational programs based on e-learning and social media. For example, in 2008, AFMC initiated the Canadian Healthcare Education Commons [61], whose mission is to provide an online environment – including wikis among other tools – to share educational material, designs, and practices in whatever form across the health care continuum and between professions in Canada.

In the Netherlands, the NPCF brings together hundreds of patient and consumer organizations to speak as one voice in areas of common interest, such as patients' rights and access to care [62]. In the NPCF's vision, eHealth is an essential enabler for real empowerment of patients and self-management of their health. Patient participation is very important for improving health care as the views and experiences of patients and consumers can be heard in order to shift towards a participatory health care model.

As designated knowledge users for this CIHR-funded research project, these three institutions (IMIA, AFMC, and NPCF) have helped define the need for this scoping review. In particular, these institutions want to explore the features that explain wikis and collaborative writing applications' rising popularity [6,16] and clarify the differences between wikis and other applications, like Google Knol [8,18,19,63,64] and Google Docs [20,22]. Specifically, these institutions need to know how various applications can enhance the delivery of health care (e.g., by empowering patients in decision making [65,66]), improve health care communication and education [13,20,38,67,68], and benefit health in developing countries [8]. These institutions intend to use this evidence to formulate policies for the applications' safe and effective use.

Gaps in the knowledge addressed by this proposal

We have seen that the rapid rise in the use of collaborative writing applications in health care has created a need for a systematic synthesis of the evidence concerning their potential impacts and an inventory of the barriers and facilitators that affect their use. A scoping review is the ideal methodology to employ for a number of reasons. According to the CIHR, a scoping review is explorative and used when the relevant literature is considered to be broad and diverse as is the expanding literature about collaborative writing applications [69]. Moreover, the study of these applications is an emerging field that is being examined with diverse methods [20,38,50], with different theoretical frameworks [21], and in different contexts [35,70]. While researchers have conducted systematic reviews on information and communication technologies [71,72] and other social media (virtual communities of practice [73], virtual peer-to-peer communities, and electronic support groups [74]), none have reviewed collaborative writing applications. Therefore, in synergy and partnership with three national and international institutional knowledge users, we propose a scoping review that will map the literature on the use of wikis and other collaborative writing applications in health care in order to synthesize the applications' positive and negative impacts and inventory the barriers and facilitators that affect how they influence the delivery of health care.

Purposes for conducting this scoping review

The overarching goal of this project is to explore the depth and breadth of evidence about the effective, safe, and ethical use of collaborative writing applications in health care systems around the world.

Specifically, the purposes of conducting this scoping review are to:

1. Map the literature on collaborative writing applications (including wikis, Google Knol, and Google Docs) in health care;
2. Compare the applications' features by investigating how they are used in collaborative writing projects;
3. Describe the evidence of each application's positive and negative effects as a knowledge translation (KT) intervention in health care;
4. Inventory and describe the barriers and facilitators that affect the applications' use; and
5. Produce an action plan and a research agenda delimitating three areas: where sufficient evidence exists to make clear and judicious policy recommendations about the use of collaborative writing applications in health care, where further knowledge synthesis is needed, and where more primary research remains to be done.

Conceptual frameworks

Since this scoping review concerns the use of collaborative writing applications as KT interventions in health care, we will use the Knowledge to Action (KTA) framework [75,76] to describe and compare the various studies and collaborative writing projects we find. We intend to use the framework as a roadmap for determining where studies of collaborative writing applications and real projects that use those applications fit along the KT continuum. The role of collaborative writing applications in KT has not yet been determined: it is possible that applications play a different role at different phases in the KTA process. For example, a wiki used to update a systematic review [34,35] would not play the same role as a wiki used to promote global public health [8], a Google Knol used to exchange knowledge about influenza [19], or Google Docs used to teach scientific writing [20]. Finding and categorizing studies and collaborative writing projects will identify gaps in the knowledge about the applications' use as KT interventions. These gaps will then inform our production of a research agenda. Finally, we will describe how the studies use different behavioral and organizational models of change [79,80] to study collaborative writing applications. We will also use the taxonomy from a systematic review on the factors affecting the adoption of information and communication technology to inventory and describe the barriers and facilitators identified in this scoping review [72].

Methods

To accomplish the purposes of this scoping review, we will employ the scoping review methodology described by Arksey and O'Malley [79] and further developed by Levac et al. [80]. This methodology has six stages: (1) identifying the research question; (2) identifying relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarizing, and reporting the results; and (6) consulting knowledge users (Figure 1).

Figure 1. Stages of the scoping view

STAGE 1: RESEARCH QUESTION IDENTIFIED
(in consultation with knowledge users)

Overarching goal: To explore the depth and breadth of evidence for the use of collaborative writing applications in healthcare.

Research question: What is the extent of the knowledge concerning the barriers to, the facilitators of, and the impacts of using collaborative writing applications as KT interventions in health care?

The purposes of this scoping review are to:

1. Map the literature on collaborative writing applications (including wikis, Google Knol, and Google Docs) in health care;
2. Compare the applications' features by investigating how they are used in collaborative writing projects;
3. Describe the evidence of each application's positive and negative effects as a knowledge translation (KT) intervention in health care;
4. Inventory and describe the barriers and facilitators that affect the applications' use; and
5. Produce an action plan and a research agenda delimitating three areas: where sufficient evidence exists to make clear and judicious policy recommendations about the use of collaborative writing applications in health care, where further knowledge synthesis is needed, and where more primary research remains to be done.

STAGE 2: IDENTIFYING RELEVANT LITERATURE (MAPPING)

1. Systematic and exhaustive searches to identify all relevant citations and grey literature concerning wikis and other collaborative writing applications; and
2. Retrieval, screening, and classification of full reports.

STAGE 3: SELECTING STUDIES AND GREY LITERATURE

1. Only literature concerning health care and involving at least one reference to "wiki" or "collaborative writing application" (or tool, or technology, etc) will be included for our map; and
2. First meeting with knowledge users: Review selected studies, suggest new sources of information, and offer guidance for the rest of the study.

STAGE 4: CHARTING THE DATA

1. Consensus on the data charting form;
2. Data extraction from citations using the data coding form built into EPPI-Reviewer;
3. Use of the metadata tagged to the citations;
4. Inductive coding allowing line-by-line coding of textual data;
5. Description of wikis in health care; and
6. Presentation of preliminary results to knowledge users.

STAGE 5: COLLATING, SUMMARIZING, AND REPORTING RESULTS
Conducted with the help of knowledge users (second meeting)

1. Summary of the studies and their characteristics (Objectives 1, 3, and 4);
2. Comparison of the features of wikis to the features of other collaborative writing applications (Objective 2); and
3. Interpretive synthesis of the present literature using the constant comparison method in order to classify each study and wiki in relation to the KTA framework, in order to:
   a. Describe the evidence on the effectiveness of wikis and other collaborative writing applications as knowledge translation tools (Objective 3);
   b. Describe the evidence on the barriers to and facilitators of using wikis and collaborative writing applications in health care (Objective 4); and
   c. Outline the gaps in the knowledge within the KTA framework (Objective 5).

STAGE 6: CONSULTING KNOWLEDGE USERS

Integrated knowledge translation: We will consult knowledge users throughout our review to ensure that results are useful and practical.

Stage 1: Identifying the research question

The research question was developed by consulting the knowledge users to determine their needs and questions about using collaborative writing applications for KT. Their questions can be summarized as follows: "What is the extent of the knowledge concerning the barriers to, the facilitators of, and the impacts of using collaborative writing applications as KT interventions in health care?" As was previously stated, and in response to this question, the overarching goal of this project is to explore the depth and breadth of evidence about the effective, safe, and ethical use of collaborative writing applications in health care systems around the world. The purposes of our scoping review will be used to attain this goal, and therefore orient our search for publications and the grey literature. The participants targeted by this scoping review are any person involved in a KT intervention in health care (e.g., patients, health care professionals, policy makers, students, educators, providers, managers, and researchers). For the purposes of our study and having referred to the writing on the subject [14-16], we have defined "collaborative writing applications" as a category of social media that enables the joint and simultaneous editing of a webpage or an online document by many end users [15]. Thus, the term covers wikis, Google Knol, and Google Docs, but does not exclude new applications for use in a future update. In terms of outcomes, our scoping review will apply no restrictions since it is important that we describe all relevant outcomes used in the literature.

Stage 2: Identifying studies and the grey literature

We will begin by comprehensively mapping publications and the grey literature to identify all sources of information within the broad remit of our overall question. To facilitate this stage, we will use software developed by the Evidence for Policy and Practice Information and Coordinating Centre (EPPI-Centre) [81]. Using EPPI-Reviewer 4.0 [81-85], we will create a database of publications and grey literature on collaborative writing applications in health care. EPPI-Reviewer is a multi-user web-based application for managing and analyzing data for use in research synthesis. The search methods that will be used for identifying studies and the grey literature are described below.

Electronic searches

We will search publications identified in the following bibliographic databases: the Cochrane Effective Practice and Organisation of Care (EPOC) Review Group Specialised Register; the Cochrane Library (including Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Database of Abstracts of Reviews of Effects, Health Technology Assessment Database, and NHS Economic Evaluation Database); EMBASE; PubMed; CINAHL; PsycINFO; Education Resources Information Center (ERIC); and ProQuest Dissertations and Theses. Our team's information specialist (KA) developed a search strategy, which was peer-reviewed by an information specialist from the Medical Library of the Radboud University Nijmegen Medical Centre in The Netherlands. The search strategy is broad enough to generate an extensive map of the literature on wikis and other collaborative writing applications. We will impose no restrictions

on language or date. Our preliminary search strategy (Appendix 1), which used the terms "wiki", "wikis", "Web 2.0", "social media", "Google Knol", "Google Docs", and "collaborative writing applications", identified 7174 citations before removal of duplicates.

Other sources

We will conduct additional searches by (1) scanning the reference lists of included studies; (2) reviewing the two most recent editions of the proceedings and abstracts of relevant conferences, symposia, and colloquia; (3) searching web-based registries of clinical trials; (4) contacting experts to request details of any known studies (e.g., the authors of WikiProject Medicine [8]); and (5) searching the following repositories of grey literature: the New York Academy of Medicine Library's Grey Literature Report, OpenSIGLE, the Health Technology Assessment international (HTAi) Vortal, and CADTH's online search engine.

We will also search for grey literature on the Internet using the search engines Google, Bing, Yahoo, Mednar, and Scopus. Google, Bing, and Yahoo are the most widely used search engines [85]; Mednar and Scopus focus on scientific content. We will use the advanced search option, select no preferred language, and turn off the option for regional differences. Based on previous research [85,86], we expect a large number of results. For this reason, when searching with Google, Yahoo, Bing, and Scopus, we will use a more specific search string query, such as "wiki in health care", "Google Knol in health care", "Google Docs in health care", and "collaborative writing applications in health care". We will study the first 100 results in Google, Bing, and Yahoo, which all display results by relevance using a link analysis system or algorithms [85]. We will then analyze the top 100 results for each search engine to identify all collaborative writing projects inventoried. We will complete our comprehensive search of the Internet by consulting existing lists of wikis in health care [23,87]. The founding authors of each identified collaborative writing project will be contacted and asked for all published or unpublished descriptions of the features of the application they used (e.g., wiki, Google Knol, or Google Docs), studies of the impacts of the application, and studies of the barriers to, and facilitators of, the use of the application.

To ensure we include all relevant studies, we will invite all interested Internet users and researchers to share papers that could potentially fall within the scope of this review. A public online Mendeley library has been created to allow anyone to make contributions to the current collection of citations. To add citations to this online library, interested individuals are invited to access the library [88]. Furthermore, if interested individuals prefer to use a wiki to share their citations, they are invited to do so by using the HLWIKI [89]. A Google Docs spreadsheet [90] will also allow potential collaborators to add citations for consideration for this scoping review. We will use these different social media resources to verify if any new citations will be identified by comparing the lists of citations created in these three resources to the lists we will be creating within EPPI-Reviewer. Any individual’s contribution to these three resources will be recognized and appropriately credited.

EPPI-Reviewer

All sources of information (publications and grey literature) will be imported into EPPI-Reviewer using the Research Information Systems (RIS) tagging format. For webpages, we will use Mendeley [91], a free online reference manager built to facilitate the tagging and describing of web-based sources of information. We will then import these tagged webpages in RIS format into EPPI-Reviewer for further analysis. All duplicates will be removed within EPPI-Reviewer.

Stage 3: Selecting studies and the grey literature

This stage will consist of an iterative process in which we search the literature, refine our search strategy, and review articles for inclusion. Two reviewers will independently screen all titles, abstracts, and grey literature in EPPI-Reviewer and retain only material concerning the field of health care and involving collaborative writing applications such as wikis, Google Knol, and Google Docs. The team's reviewers will meet at the beginning, during the middle, and at the end of the review process to discuss their selection of literature and to refine the search strategy, if needed. Two reviewers will then independently review full articles and grey literature for inclusion. If they disagree, a third reviewer will arbitrate. EPPI-Reviewer will facilitate consensus by allowing multiple users to classify studies independently before comparing their results. EPPI-Reviewer will also produce summary discrepancy reports. Its interface will facilitate final decisions.

Stage 4: Charting the data

We have already developed a preliminary data-charting form and determined which information to extract. This form will be built into EPPI-Reviewer to facilitate our coding of data. Two authors will use the form to extract data from the first 10 studies and/or grey literature independently before meeting to determine whether their approach to data extraction is consistent with the research question and the purpose of the review. Thus, for the first 10 sources of information, charting will be an iterative process in which researchers continually update the data-charting form. Once the reviewers reach consensus on the form, they will send it to all team members for final comments and suggestions, after which the reviewers will use it to extract data for each publication. The reviewers will compare their extraction results within EPPI-Reviewer. If they disagree, a third reviewer will determine the final version of the data extracted.

Using EPPI-Reviewer's inductive coding function, which allows textual data to be coded line-by-line, and using the metadata already tagged to each citation in RIS format, two reviewers will qualitatively describe the sources of information with regard to the following variables: authorship, year of publication, country, status of publication (i.e., published or grey literature), journal, Medical Subject Headings (MeSH) terms used, participants (patients, health care professionals, policy makers, educators, or students), study setting, study design (e.g., experimental, non-experimental, or qualitative), collaborative writing application used in the intervention group, goal of the intervention (conducting reviews, developing guidelines, promoting evidence-based practice, promoting evidence-informed policy making, promoting shared decision

making, or teaching health care), description of the comparison, description of the outcomes, description of the positive and negative impacts, description of barriers and facilitators, use of a behavioral or organizational theory of change to describe barriers and facilitators. For every collaborative writing project that involved the use of a collaborative writing application, we will code the following variables: website address, audience, contributors, editors, supporting organization, editorial policy, recognition of authorship, presence of publicity, number of pages, language, type of content, application used (e.g., wiki software), references to published descriptions, references to studies assessing the project's impact, and references to studies on barriers and facilitators. Using EPPI-Reviewer, we will compare the reviewers' coding to ensure that our results are trustworthy. Any discrepancy will be resolved by discussion. If consensus is not possible, a third reviewer will decide.

Stage 5: Collating, summarizing, and reporting results

Collating and summarizing

As described in the framework by Arksey and O'Malley [79], our analysis (referred to as "collating and summarizing") will involve a descriptive numerical summary and an interpretive synthesis. First, we will summarize the studies and their characteristics as described in the charting stage (Purposes 1, 3, and 4). This description will constitute our map of the literature on collaborative writing applications in health care. We will report the frequency of studies according to variables defined in Stage 4, such as the study design, the type of intervention that took place, the outcomes that were measured (health care process outcomes or health outcomes), the positive and negative impacts, the barriers and facilitators, and the explicit use (or non-use) of a theoretical framework.

Our description of impacts (Purpose 3) will remain qualitative and will serve to identify the potential for future systematic reviews. Examples of impacts are an increase in professionalism by medical students (a positive impact) [38] and the dissemination of inaccurate information on HIV/AIDS medication (a negative impact) [50]. We will begin our description by developing a coding scheme using qualitative content analysis, a method whereby researchers interpret textual data subjectively by systematically classifying and coding data and identifying patterns [92]. Using a random sample of 10% of all data, two reviewers will identify the positive and negative impacts mentioned by the studies and mark recurrent impacts with codes [92]. They will begin by reading the data repeatedly to immerse themselves and obtain a broad perspective [93]. Then, with EPPI-Reviewer's full text mining capacity, they will read the content word-by-word, highlighting words that appear to capture impacts and assigning them codes, which they will then organize into categories. They will also develop a tree diagram to organize the categories into a hierarchical structure [94]. Next, we will develop definitions for each code and category. These codes and categories will constitute our coding scheme and will guide reviewers' content analysis of the rest of the data. The two reviewers will discuss units of text that could not be coded and will create new codes as necessary.

Our description of barriers and facilitators (Purpose 4) will be based on a validated taxonomy developed by Gagnon et al. [72]. The reviewers will read each publication independently and identify the unit of text (a sentence or paragraph representing an idea) relevant to each main outcome of interest (barriers and facilitators). Using EPPI-Reviewer, they will then code each unit of text according to the code list. If necessary, the reviewers will create new codes for units of text that cannot otherwise be coded, thus refining and expanding the list. The reviewers will resolve any coding discrepancies through discussion. During the coding process, codes will be aggregated into themes, which will be nested under a main theme.

The same constant comparison method [92] will be used to compare the features of the collaborative writing applications by analyzing their use in different collaborative writing projects (Purpose 2). Again, a coding scheme will be developed from a random sample of 10% of the data, following the process used for coding impacts. In this case, the categories will correspond to meaningful clusters that reflect the relationships between the applications' features. We will code the data using this scheme, as per the process described previously. We will also construct a table that compares the collaborative writing applications used for each project and identifies the presence or absence of features using the developed coding scheme. The resulting synthesis will allow knowledge users – IMIA, AFMC, and NPCF in particular – to make recommendations for the use of the applications that more accurately reflect the applications' strengths and weaknesses.

Also using the constant comparison method, we will perform directed content analysis [92] to classify each project that used a collaborative writing application in relation to the KTA framework. The KTA framework will serve as a map on which collaborative projects will be plotted according to each project's explicit or implicit goal as interpreted by the reviewers' analysis of the project's features and characteristics. Thus, each project will occupy a space within the KTA framework that reflects the phase of the KTA framework that the project is likely to influence. The KTA framework will describe the phases and detail the relationships between them, helping to determine the initial coding scheme. Projects that cannot be coded will be identified and analyzed later to determine whether they represent a new process within the KTA framework or a subcategory of an existing process. This directed approach to content analysis will allow us to validate the KTA framework for the study of future collaborative writing projects. It will also allow the KTA framework to be extended if new processes or subprocesses are identified.

The conceptual framework generated by our directed content analysis will allow us to classify applications according to the phase of the KTA process that they influence. It will do likewise for applications' positive and negative impacts (Purpose 3) and the barriers to, and facilitators of, using the applications as KT tools in health care (Purpose 4). In addition, the analysis will guide: (1) our formulation of clear, evidence-based policies where sufficient evidence exists about the use of wikis and other collaborative writing applications as KT interventions; (2) our analysis of gaps in

the knowledge; and (3) our identification of areas where more primary research is needed and areas where there is enough data to conduct systematic reviews (Purpose 5).

Reporting results

To present the results of our qualitative analyses, we will employ descriptive tables, frequency tables, and diagrams. A table will describe the characteristics of each study included in our review. Additional tables will classify the studies according to their principal characteristics: participants, study setting, study design, study intervention, aim of the collaborative writing applications, and outcomes studied. A summary table will group those studies that assessed the impacts of the use of a collaborative writing application, showing the phase of the KTA process that the application influenced and describing the studies' results. Another summary table will present all the studies that assessed barriers and facilitators, the theory used by each, the KTA process influenced, and – using a validated taxonomy – a description of the barriers and facilitators found. These tables will be useful for knowledge users interested in the impacts of using collaborative writing applications in health care and on the barriers and facilitators that affect their use. To compare applications, a Venn diagram will be constructed that situates each application in relation to the others. This will help knowledge users understand how each application can be used. Finally, a diagram that situates the different collaborative writing applications within the KTA framework will help knowledge users understand the applications' role in KT. This conceptual map will be very useful in designing systematic reviews and primary studies in the future.

Stage 6: Consulting knowledge users

Our scoping review will involve the knowledge users throughout the review's duration in order to generate usable and practical results. This integrated KT model is important to giving the review perspective, meaning, applicability, and a clear purpose. By laying out their needs for the products of this review, knowledge users have already shaped our research purposes. We will continue to involve knowledge users by conducting two teleconferences during the course of the review. In the first teleconference (after Stage 3), we will share the preliminary findings of the review to validate our findings and guide the review's completion. This meeting will be an opportunity for IMIA, AFMC, and NPCF to identify additional sources of information that we should consider. The second, and final, meeting will be held near the end of Stage 5, when we will use the preliminary findings from Stage 5 (presented in tables and diagrams) as a foundation for the formulation of an action plan and a research agenda (Purpose 5). Our knowledge users will have the opportunity to build on the evidence presented and offer more meaning, content expertise, and perspective to the preliminary findings. These meetings will guide our writing of the final report and the two-page policy briefs that knowledge users find accessible and useful.

Discussion

This review will generate results that will be highly pertinent to the knowledge users who will collaborate on the project, as well as to the broader community they represent. In general, it will draw upon the evidence to refine the community's understanding of the use of collaborative writing applications as KT instruments. First, it will identify the features that differentiate collaborative writing applications; second, it will discuss the positive and negative impacts of different collaborative writing applications and the barriers and facilitators that affect their use. Using the KTA framework, we will group the applications by KTA phase. This will allow us to produce a strategic action plan that is grounded in knowledge users' feedback and makes recommendations about the use of collaborative writing applications as KT interventions where justified by the evidence. Also, it will allow us to develop a research agenda that can identify areas that need more systematic review or primary research. Ultimately, we expect our findings to benefit knowledge users in health care organizations around the world, especially in developing countries where clinicians are most likely to value applications that share free, reliable, health information. The review will also help build a strong partnership between knowledge users and scientists, which will be useful for further research. Furthermore, knowledge users and researchers around the world are invited to pursue this endeavor in collaboration with us by contributing to the synthesis of new knowledge on wikis and collaborative writing applications in health care. This novel use of crowdsourcing to identify citations and to update the database of citations created with this study will add to the results of ongoing studies concerning the potential use of crowdsourcing to supplement the process of knowledge synthesis and scoping reviews [95,96]. In addition to contributing to the guidance on the use of collaborative writing applications, this scoping review will advance the science of KT by testing and improving tools that could be used to evaluate other social media. In particular, this review will be the first to use the KTA framework to study the role of collaborative writing applications in KT. Using this framework will help us determine a research agenda that will be instrumental in future explorations of applications such as wikis, Google Knol, and Google Docs.

Conclusions

For all the promise and power of collaborative writing applications for KT, the applications are also fraught with important barriers and the potential of adverse effects. This argues for rapid guidelines for the implementation and development of these new social media. To date, this is the first study that will use the KTA framework to examine the role collaborative writing applications can play in KT. It is also the first to involve three national and international institutional knowledge users – IMIA, AFMC, and NPCF – in the process.

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Appendix 1

Definitive search term strategy in different databases and number (n) of citations found for each database (October 2011).

1- Pubmed (n=1061): Wiki*[All Fields] OR "Web 2.0"[TIAB] OR "Web2.0"[TIAB] OR (google* AND knol) OR (google* AND docs) OR "Social media"[TIAB] OR (Collaborative [tiab] AND writing [tiab]) OR (collaborative technolog*) OR (collaborative software*)
2- Embase (n=1059): wiki* OR 'collaborative technology' OR collaborative technologies' OR 'collaborative writing' OR 'collaborative writings' OR 'collaborative software' OR 'collaborative softwares' OR 'google docs' OR 'google knol' OR 'ehealth 2.0' OR 'health 2.0' OR 'e+health 2.0' OR 'web 2.0'
3- CINAHL (n=1462): TI ((wiki* or "google docs" or "google knol" or "medecine 2.0." or "web 2.0" or "collaborative technolog*" or "collaborative writing" or "ehealth" or "e-health" or emedicine or "e-medicine")) OR AB ((wiki* or "google docs" or "google knol" or "medecine 2.0." or "web 2.0" or "collaborative technolog*" or "collaborative writing" or "ehealth" or "e-health" or emedicine or "e-medicine"))
4- PsychINFO (n=1124): (wiki* or "google docs" or "google knol" or "collaborative software" or "collaborative writing" or "collaborative technologies" or "collaborative techonology"):Any Field OR ("medicine 2.0" or "emedicine" or e-medicine or "health 2.0" or "ehealth" or e-health or "web 2.0"):Title OR ("medicine 2.0" or "emedicine" or e-medicine or "health 2.0" or "ehealth" or e-health or "web 2.0"):Abstract
5- ERIC (n=1780): ((Keywords:wiki* or Keywords:"web 2.0" or Keywords:"google docs" or Keywords:"google knol" or Keywords:"collaborative technologies" or Keywords:"collaborative technology" or Keywords:"collaborative software" or Keywords:"collaborative writing" or Keywords:"e-health" or Keywords:ehealth) or (Title:wiki* or Title:"web 2.0" or Title:"google docs" or Title:"google knol" or Title:"collaborative technologies" or Title:"collaborative technology" or Title:"collaborative software" or Title:"collaborative writing" or Title:"e-health" or Title:ehealth) and (Thesaurus Descriptors:"Health services"))
6- Dissertation abstract & Thesis (n=632): Citation & Abstract (wiki* or "health 2.0" or "web 2.0" or "e-medicine" or emedicine or "google docs" or "google knol" or "collaborative technologies" or "collaborative technology" or "collaborative writing" or "collaborative software")
7- Cochrane Library (n=56): (wiki* or "web 2.0" or ehealth or "e-health" or "google docs" or "google knol" or "collaborative writing") in Title, Abstract or Keywords in All Cochrane Library

TOTAL NUMBER OF CITATIONS: 7174 (no duplicates removed)

6

Wikis and Collaborative Writing Applications in Health Care: A Scoping Review

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Abstract

Background: Collaborative writing applications (e.g., wikis and Google Documents) hold the potential to improve the use of evidence in both public health and health care. The rapid rise in their use has created the need for a systematic synthesis of the evidence of their impact as knowledge translation (KT) tools in the health care sector and for an inventory of the factors that affect their use.

Objective: Through the Levac six-stage methodology, a scoping review was undertaken to explore the depth and breadth of evidence about the effective, safe, and ethical use of wikis and collaborative writing applications (CWAs) in health care.

Methods: Multiple strategies were used to locate studies. Seven scientific databases and 6 grey literature sources were queried for articles on wikis and CWAs published between 2001 and September 16, 2011. In total, 4436 citations and 1921 grey literature items were screened. Two reviewers independently reviewed citations, selected eligible studies, and extracted data using a standardized form. We included any paper presenting qualitative or quantitative empirical evidence concerning health care and CWAs. We defined a CWA as any technology that enables the joint and simultaneous editing of a webpage or an online document by many end users. We performed qualitative content analysis to identify the factors that affect the use of CWAs using the Gagnon framework and their effects on health care using the Donabedian framework.

Results: Of the 111 studies included, 4 were experimental, 5 quasi-experimental, 5 observational, 52 case studies, 23 surveys about wiki use, and 22 descriptive studies about the quality of information in wikis. We classified them by theme: patterns of use of CWAs (n=26), quality of information in existing CWAs (n=25), and CWAs as KT tools (n=73). A high prevalence of CWA use (i.e., more than 50%) is reported in 58% (7/12) of surveys conducted with health care professionals and students. However, we found only one longitudinal study showing that CWA use is increasing in health care. Moreover, contribution rates remain low and the quality of information contained in different CWAs needs improvement. We identified 48 barriers and 91 facilitators in 4 major themes (factors related to the CWA, users' knowledge and attitude towards CWAs, human environment, and organizational environment). We also found 57 positive and 23 negative effects that we classified into processes and outcomes.

Conclusions: Although we found some experimental and quasi-experimental studies of the effectiveness and safety of CWAs as educational and KT interventions, the vast majority of included studies were observational case studies about CWAs being used by health professionals and patients. More primary research is needed to find ways to address the different barriers to their use and to make these applications more useful for different stakeholders.

Introduction

Health care decision makers – providers, patients, managers, and policy makers – are failing to use research evidence to inform their decisions [1]. By involving knowledge users in the creation and dissemination of knowledge [2], social media – highly accessible, Web-based, interactive vehicles of communication – have the potential to empower users to apply knowledge in practice. Acknowledging this potential and recognizing that social media capitalizes on the free and open access to information, scientists, opinion leaders, and patient advocates have called for research to determine whether social media can equip decision-making constituencies to improve health care delivery [3,4] decrease its costs [2,5,6], accelerate knowledge discovery [7-11], and improve access to knowledge within developing countries [4,12-17].

Collaborative writing applications (CWAs) [18,19] are a category of social media that has surged in popularity in recent years, including within the health care sector [2,6,18,20]. CWAs consist of software that allows users to create online content that anyone who has access can edit or supplement [21]. With these contributions, CWAs can become rich multimodal communication tools enriched with hyperlinks, images, videos, and audio. For example, Internet users have turned to wikis [22,23] to produce a Wikipedia entry on the Global Plan to Stop Tuberculosis [4]; to Google Knol [24,25] to exchange research on influenza at the Public Library of Science [26]; and to Google Docs [19,27] to review the literature on emergency medicine [28,29]. Although now defunct, Google Knol was a Google project that aimed to include user-written articles on a range of topics that could be edited only if the original authors gave access to editing the text. CWAs can also be classified based on who has access. There are open or public CWAs such as Wikipedia, which can be edited by anyone in the world and can also be seen by anyone. There are also partially public CWAs, which can be seen by anyone, but can be edited only by certain members of a restricted community (e.g., Ganfyd [30]). There are also closed or private CWAs, part of central knowledge management systems (e.g., Intelink [31]) or online learning systems (e.g., Blackboard [32]), which are edited by members of the institution and are visible only to members of the institution.

Among the types of CWAs, wikis and its most famous representative – Wikipedia – are perhaps the most popular. Wikipedia is an online encyclopedia whose medical articles are viewed about 150 million times per month and exist in 271 languages [4]. Moreover, readership of Wikipedia's medical content is continuing to increase [33]. New wikis have appeared in all fields of health care [18,28,34-41], and studies of developed countries report 70% of junior physicians using Wikipedia weekly [42]. Patients use wikis to share their experiences [43] and to find information [4]. The Canadian Agency for Drugs and Technologies in Health is exploring the use of wikis to update knowledge syntheses [44-46]; the United States' National Institutes of Health is training its scientists in editing them [47,48]; and the World Health Organization is using a wiki format to update the International Classification of Diseases [49]. In addition, academic institutions have started using wikis to train health professionals [18,22,32,50-54]. Wikis have come to exemplify

social media's tremendous promise to enable health professionals, patients, and policy makers to implement evidence-based practice at remarkably low cost [5,28,29,55,56]. In doing so, they could contribute to improving the health of millions of people around the world [4,13].

However, questions remain about the safety [57-59], reliability [60-64], lack of traditional authorship [65,66], and the legal implications for decision making [67,68] regarding the use of CWAs in health care. Researchers question clinicians' intentions to use the applications in their practice [28] and to contribute knowledge collaboratively [4,29,69]. Furthermore, it is unknown how CWAs can enhance the delivery of health care (e.g., by empowering patients in decision making [70,71], by improving health care communication and education [18,27,32,72-75]), and benefitting health in developing countries [4,76]. While researchers have conducted systematic reviews on Internet and communication technologies (ICTs) [77,78], social media in health care [79-84] and research on Wikipedia in general [85], none have specifically focused on wikis and CWAs in health care. Not all social media share the same mechanisms of action [21], therefore examining CWAs in health care is important. The overarching goal of this project was to explore the depth and breadth of evidence about the effective, safe, and ethical use of wikis and CWAs in health care. We conducted a scoping review with the following specific objectives: (1) to map the literature on the use of wikis and other CWAs in health care, (2) to compare the applications' features by investigating how they were used in collaborative writing projects, (3) to synthesize the applications' positive and negative effects as knowledge translation interventions in health care, (4) to inventory the barriers and facilitators that affect how they influence health care delivery, and (5) to produce a research agenda delimiting areas where further knowledge synthesis is needed and where more primary research remains to be done.

Methods

Overview

A detailed description of our peer-reviewed research protocol and conceptual framework can be found elsewhere [86]. This review was planned, conducted, and reported in adherence to standards of quality for scoping reviews [87,88]. A summary of our six-stage methodology follows.

Stage 1: Identifying the research question

Our research question was developed by consulting a group of knowledge users to determine their needs and questions about using collaborative writing applications for knowledge translation. We defined "collaborative writing applications" as a category of social media that enables the joint and simultaneous editing of a webpage or an online document by many end users (e.g., wikis, Wikipedia, Google Knol, Google Docs, Google Sites) [21]. The participants targeted by this scoping review were health care stakeholders.

Stage 2: Identifying studies and grey literature

Seven scientific databases (Cochrane Library, PubMed, EMBASE, CINAHL, PsycINFO, ERIC, ProQuest Dissertations and Theses) were searched systematically for the period covering January 1, 2001 (Wikipedia's inaugural year), to September 16, 2011. Our search strategy was peer-reviewed using the PRESS criteria [89]. The following keywords were used and adapted to each database: "wiki", "wikis", "Web 2.0", "social media", "Google Knol", "Google Docs", and "collaborative writing applications" (see Table 1).

Table 1. Full search strategy for each database

Pubmed	Wiki*[All Fields] OR "Web 2.0"[TIAB] OR "Web2.0"[TIAB] OR (google* AND knol) OR (google* AND docs) OR "Social media"[TIAB] OR (Collaborative [tiab] AND writing [tiab]) OR (collaborative technolog*) OR (collaborative software*)
Embase	wiki* OR "collaborative technology" OR "collaborative technologies" OR "collaborative writing" OR "collaborative writings" OR "collaborative software" OR "collaborative softwares" OR "google docs" OR "google knoll" OR "ehealth 2.0" OR "health 2.0" OR "e+health 2.0" OR "web 2.0"
CINAHL	TI ((wiki* or "google docs" or "google knol" or "medecine 2.0." or "web 2.0" or "collaborative technolog*" or "collaborative writing" or "ehealth" or "e-health" or emedicine or "e-medicine")) OR AB ((wiki* or "google docs" or "google knol" or "medecine 2.0." or "web 2.0" or "collaborative technolog*" or "collaborative writing" or "ehealth" or "e-health" or emedicine or "e-medicine"))
PsychINFO	(wiki* or "google docs" or "google knol" or "collaborative software" or "collaborative writing" or "collaborative technologies" or "collaborative techonology"):Any Field OR ("medicine 2.0" or "emedicine" or e-medicine or "health 2.0" or "ehealth" or e-health or "web 2.0"):Title OR ("medicine 2.0" or "emedicine" or e-medicine or "health 2.0" or "ehealth" or e-health or "web 2.0"):Abstract
ERIC	((Keywords:wiki* or Keywords:"web 2.0" or Keywords:"google docs" or Keywords:"google knol" or Keywords:"collaborative technologies" or Keywords:"collaborative technology" or Keywords:"collaborative software" or Keywords:"collaborative writing" or Keywords:"e-health" or Keywords:ehealth) or (Title:wiki* or Title:"web 2.0" or Title:"google docs" or Title:"google knol" or Title:"collaborative technologies" or Title:"collaborative technology" or Title:"collaborative software" or Title:"collaborative writing" or Title:"e-health" or Title:ehealth) and (Thesaurus Descriptors:"Health services"))
Dissertation abstract & Thesis	Citation & Abstract (wiki* or "health 2.0" or "web 2.0" or "e-medicine" or emedicine or "google docs" or "google knol" or "collaborative technologies" or "collaborative technology" or "collaborative writing" or "collaborative software")
Cochrane Library (n=56)	(wiki* or "web 2.0" or ehealth or "e-health" or "google docs" or "google knol" or "collaborative writing") in Title, Abstract or Keywords in All Cochrane Library
Google, Bing, and Yahoo (n=1200 in total)	"wiki in health care"; "Google Knol in health care"; "Google Docs in health care"; "collaborative writing applications in health care"

We did not exclude any citations based on language. In addition, study reference lists; the 2010 and 2011 editions of the Medicine 2.0, WikiSym, and American Medical Informatics Association conference proceedings; clinicaltrials.gov and Open Medicine's websites; expert consultation (e.g., the authors of WikiProject Medicine [4]), OpenSIGLE (before 2005), and the Health Technology Assessment international Vortal were searched. Furthermore, environmental scans of the grey

literature indexed by Google, Bing, Yahoo, and Mednar were performed. Finally, via email, Twitter, Mendeley, Google Docs, and a health librarianship page (HLWIKI), we called for the crowdsourcing of studies that could potentially fall within the scope of this review.

Stage 3: Selecting studies

Three teams of 2 reviewers (SR/MF, TB/AB, PA/CK) independently screened titles, abstracts, and grey literature and retained articles that presented empirical data about any CWA applied to the field of health care. In case of disagreements, a third reviewer was consulted (PA, TB or SR). To reach a high level of agreement, we conducted 4 series of assignments (400 abstracts in total) whereby the screening of a number of studies was followed by a teleconference to reach agreement about which studies to include and to discuss uncertainties. Once consensus was reached for all cases, the remaining studies were coded by the same 3 pairs of screeners (SR/MF, TB/AB, PA/CK). Subsequently, 2 reviewers (TB and PA) conducted another round of screening based on full text studies. As a result, a narrowed definition of health care was applied in order to focus the analysis. Hence, studies that concerned the care of patients were included and those from the fields of basic medical sciences, the conduct of clinical trials, biomedical library science and medical informatics were excluded.

Stage 4: Charting the data

A data-charting form was developed and built into EPPI-Reviewer for the extraction of quantitative and qualitative variables and to facilitate data coding. It was tested and refined by 4 reviewers (PA, CN, ME, CF) using the first 50 studies. Three pairs of 2 reviewers (CN/CF, CN/ME, ME/CF) then independently extracted data from the remaining studies. Disagreements were resolved through discussion with a third reviewer (PA or TB). Using EPPI-Reviewer's inductive coding function, we extracted all the pre-planned variables described in our published protocol [86].

Stage 5: Collating, summarizing, and reporting results

Themes overviews

We summarized the included studies in a table comparing each of the study's characteristics. Attempting to present an organized description of the current literature on the use of CWAs in health care, we grouped studies based on purpose. Three emergent themes were the use patterns of CWAs (theme 1), quality of information found in different CWAs (theme 2), and CWAs used as knowledge translation interventions (theme 3). We also added a description of each of the applications' features (the type of CWA and software used) to examine CWA use among studies (Objective 2).

To compare the different CWA applications identified, a Venn diagram was constructed to situate each application in relation to the others depending on two features: their collaborative writing features and their conversational features. To create the most reliable representation of how different CWAs could be represented in relation to each other, each CWA was assessed by

2 reviewers using a scoring system we created based on a classification proposed by Kaplan et al. [21]. We attributed a score of 1-5 to characterize the extent of their collaborative writing features and a score of 1-5 to measure the extent of their conversational features. To design our Venn diagram, we plotted each different CWA on a graph presenting the conversational features score on the x axis and the collaborative writing score on the y axis.

Theme 1: Use patterns of CWAs

Studies whose purpose was to describe the users and the frequency of CWA use were grouped together. We compared each study in a table presenting the population surveyed, the response rate of the population surveyed, the reported results, the prevalence of use, the contribution rate, the time of assessment, and the purpose of CWA use. We also used Eysenbach's Medicine 2.0 map [2] to illustrate the extent to which the different CWAs described in the included studies involve three major stakeholder groups (consumers/patients, professionals and researchers).

Theme 2: Quality of information in different CWAs

We synthesized papers that evaluated the quality of information in CWAs by constructing a table presenting a summary of each evaluation. Three reviewers (PA, TB, SG) assigned a score on a three-point scale based on the original authors' own recommendations about future use of information contained in the different CWAs. When authors concluded that the information contained within the collaborative writing project was of high quality and that it could be used in medical decision making, we gave the paper a score of 1. When the authors concluded that the information reported was not reliable and should never be used in decision making, a score of 3 was attributed. When authors were uncertain and/or suggested that more research was needed, a score of 2 was given. This score was attributed after discussion between the three reviewers until consensus was achieved.

Theme 3: CWAs used as knowledge translation interventions

Positive/Negative effects

Three reviewers (PA, TB, SG) performed a mixed inductive and deductive thematic analysis of the content coded in Stage 4 to classify and interpret the perceived positive and negative effects related to the use of a CWA. They began by developing a coding scheme using qualitative content analysis, a method whereby reviewers interpreted the data subjectively by classifying and coding data and identifying patterns [90]. Then, they read the data charted in Stage 4 repeatedly to immerse themselves and obtain a broad perspective [91]. Subsequently, using constant comparison methodology [90], they read the coded content by each reviewer in Stage 4, highlighting words that captured the positive or negative effects. A matrix was created to present any positive or negative effect reported in each study. We then assigned these effects specific codes, organized them into broad categories, and developed a tree diagram to organize the categories into a hierarchical structure [92]. We consolidated codes and categories that expressed the same idea into a comprehensive coding scheme that constituted our taxonomy and guided

reviewers' content analysis of the rest of the data. The three reviewers discussed units of text that could not be coded with existing codes and created new codes if necessary. The Donabedian framework [93] for quality improvement informed the classification of positive and negative effects into processes and outcomes. Elements from the Theoretical Domains Framework [94] were drawn from to classify effects of CWAs on behavior. In order to produce a comprehensive taxonomy for all described positive and negative effects of CWAs in the health care field, we added new items to our taxonomy whenever any unique item was found in a paper. Whenever these items came from a specific theoretical framework, we noted the name of the framework and attempted to label the item using the same terminology as the original source framework.

Barriers/facilitators

A second thematic content analysis was performed on the data regarding barriers and facilitators to the use of CWAs in health care with the initial coding scheme reflecting an existing framework concerning the determinants of ICT adoption [78]. Many new determinants of social media were inductively added to this framework. Our 3 reviewers created new codes for units of text that could not otherwise be coded using the original framework, thus refining and expanding the list. We also systematically searched each article to determine if a theoretical framework was used to report barriers and facilitators. If so, relevant elements were also added to the existing framework.

Stage 6: Consulting knowledge users

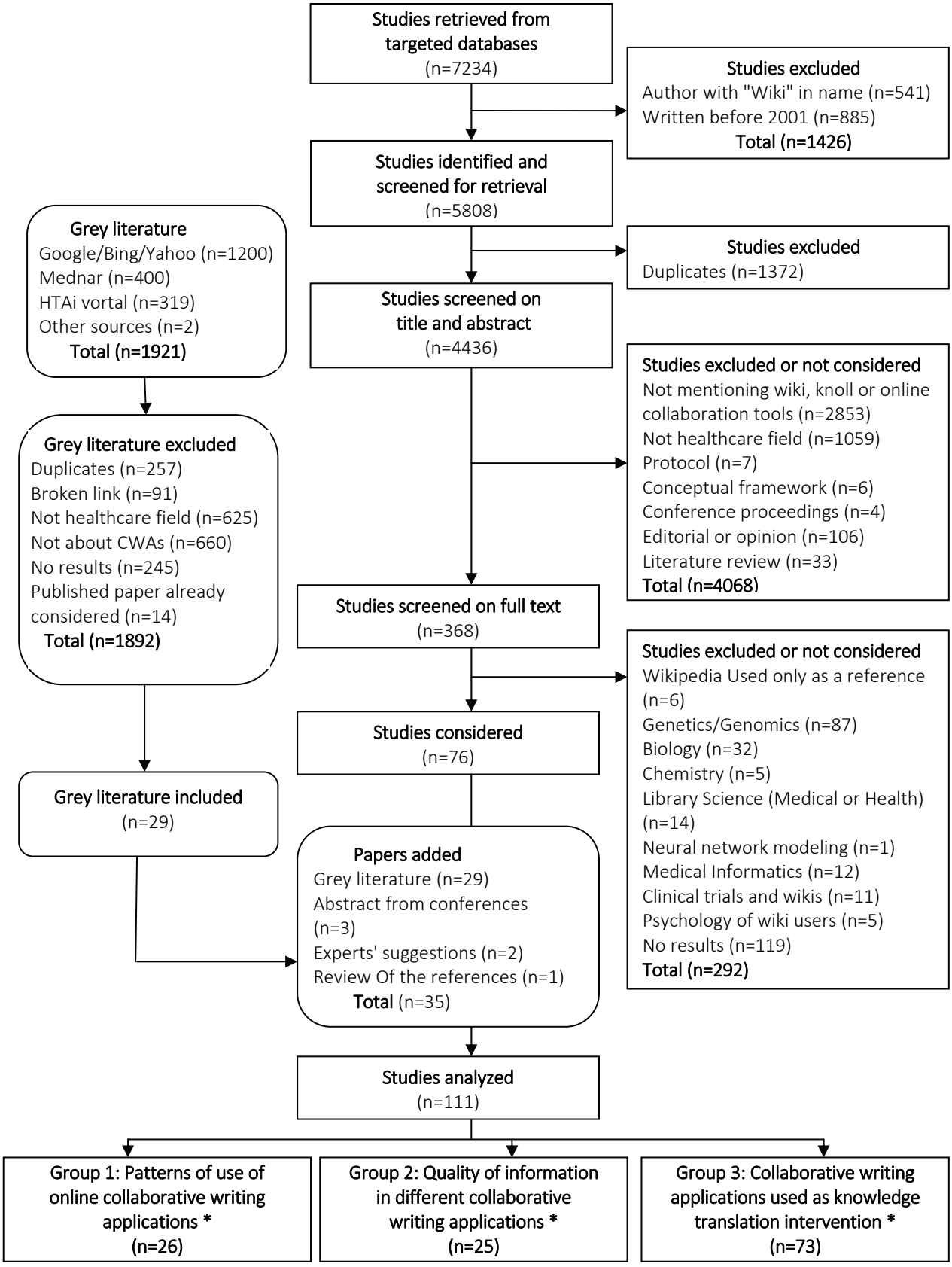
As specified in our published protocol [86], we held meetings with representatives from the organizations involved (i.e. the Association of Faculties of Medicine of Canada (AFMC), the International Medical Informatics Association (IMIA), the Federation of Patients and Consumer Organization in the Netherlands (NPCF), and the Pan American Health Organization (PAHO)) at the beginning, midway, and draft manuscript stages of this research in order to generate results that were useful for these knowledge users. Knowledge users were selected to represent a broad range of potential stakeholders representing medical education (AFMC), public health (IMIA and PAHO), and patient representatives (NPFCF).

Results

Stages 1, 2 and 3: Mapping of the literature and study selection

After removing duplicates (n=1372), we screened the title and abstract of 4436 citations as well as the studies/abstracts from the grey literature, conference proceedings, expert consultation and reviewing of reference lists (Figure 1). All disagreements (n=794) were resolved through discussion.

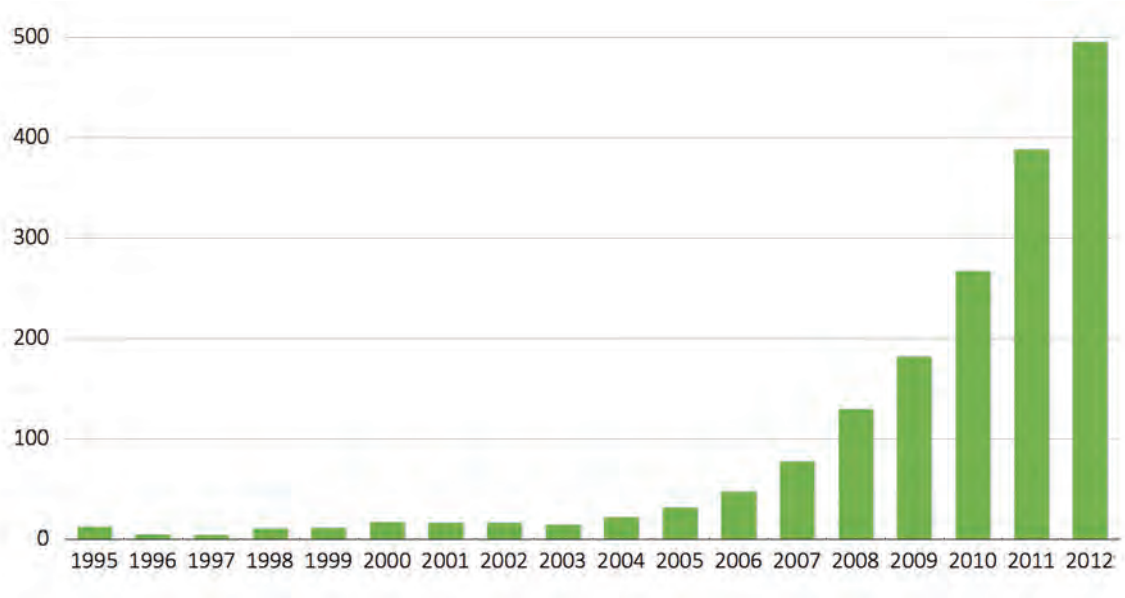
Figure 1. Flow chart of our mapping process and study selection



*10 papers are classified in two groups, and 1 is classified in all three groups

Crowdsourcing identified two studies through Google Docs that were excluded. After review, we included 111 citations. Among these 111 citations, there were 28 abstracts without published full text but with sufficient results to be included. Twenty-six studies were grouped into Theme 1 (use patterns of CWAs), 25 into Theme 2 (quality of information in different CWAs), and 73 into Theme 3 (use of CWAs as a knowledge translation intervention). Figure 2 shows the rapid growth of the number of publications for the period within our search strategy.

Figure 2. Histogram of the number of publications related to our search strategy per year



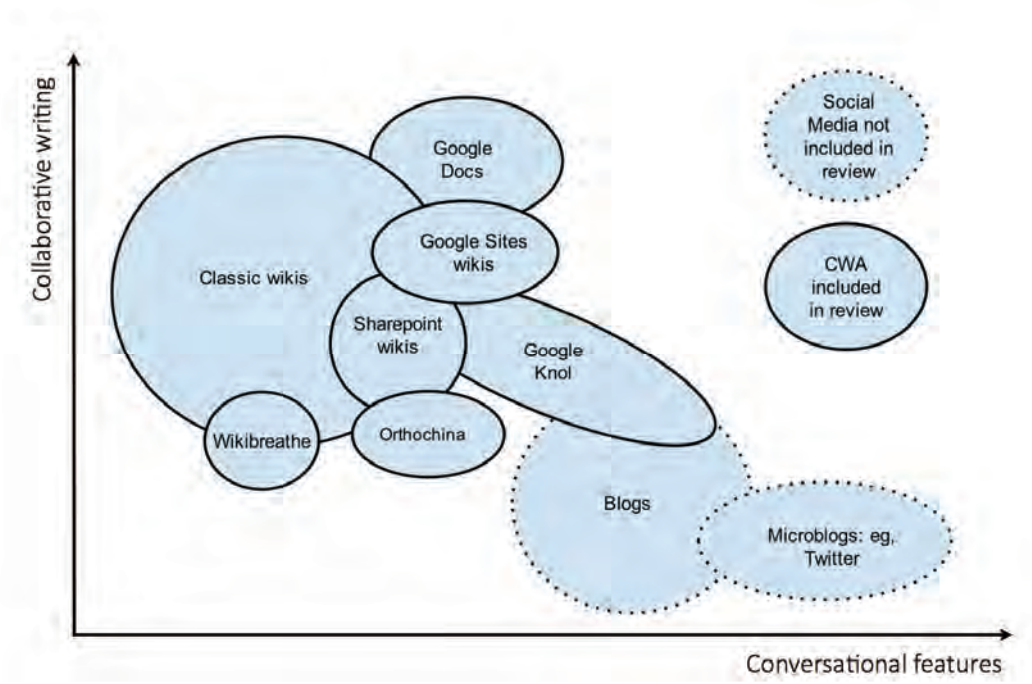
Stage 4 and 5. Charting data, collating, summarizing and reporting results

Study characteristics

We found 4 experimental studies, 5 quasi-experimental, 5 observational analytic, 52 case studies, 22 describing the quality of wikis, and 23 surveys on wiki use (Appendix 1; [27,29-32,38,42,53,54, 58,61,63,72,74,76,95-262]). Wikis (n=106) and Google Docs (n=6) are the main types of CWAs used in health care. One grey literature report compared Google Knol to Wikipedia [96]. Wikipedia was the focus of a large number of studies (n=36). The most frequently used wiki software were MediaWiki (n=44), PBworks (n=8), Wikispaces (n=6), Wetpaint (n=6), Microsoft SharePoint (n=3) and Google Sites (n=3). One paper described two wikis using Semantic MediaWiki (WikiEcho [97] and WikiDoc [98,99]). There were studies describing custom-built hybrid wikis (Wikibreathe (n=2) [100,101], Orthochina (n=1) [102], and FreyaWIKI (n=1) [103]; the use of virtual learning environments (e.g., Blackboard) to host wikis as aids for supporting educational activities (n=8); and the use of more sophisticated social media platforms (e.g., Drupal [104], MijnZorgNet [105], Atlassian [76], and MinJournal [106]) that offer wikis and other social media such as blogs and social networking services. The importance of the collaborative writing features compared to conversational features for each of the CWA studied are presented in a Venn Diagram (Figure 3). This diagram shows that wikis and other hybrid wikis are centered more on their collaborative

writing features compared to Google Knol, whose conversational features stand out more. Google Docs is different in that it offers both collaborative writing features (e.g., real-time online editing) and conversational features (e.g., linking documents to authors' email allowing them to discuss a document while it is being created).

Figure 3. Collaborative writing application Venn diagram



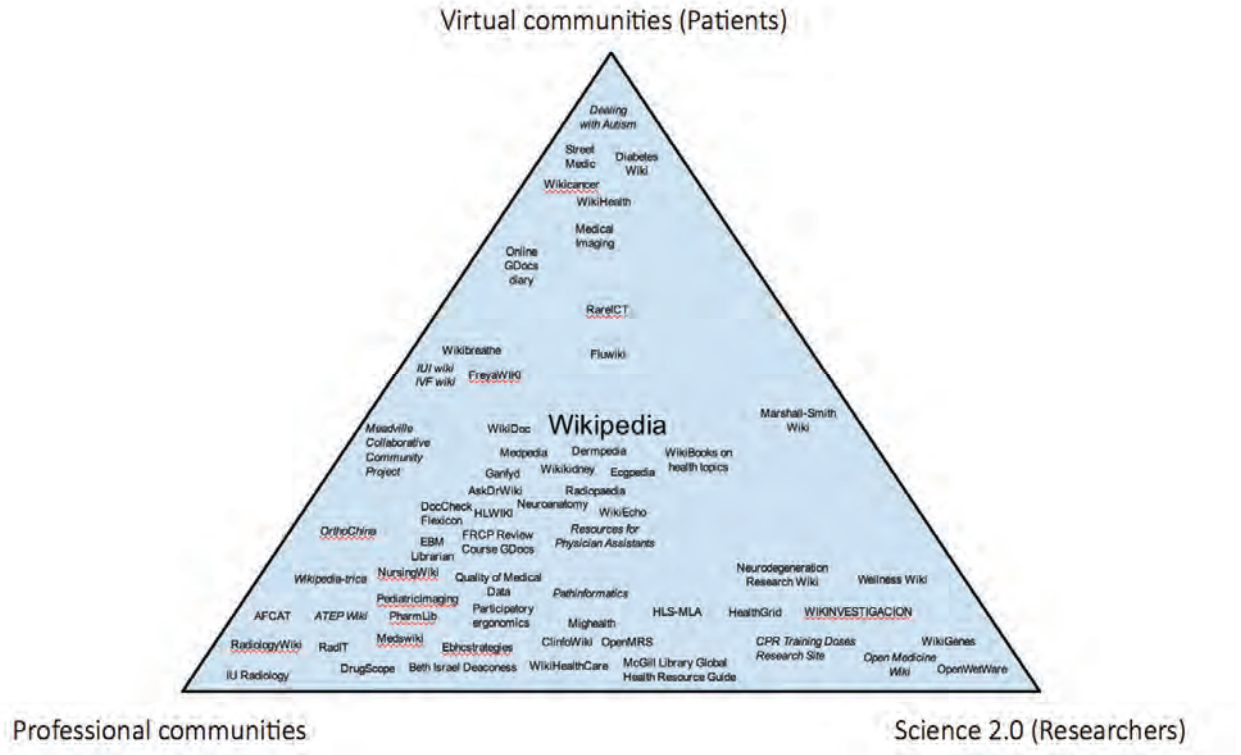
Two of the six studies pertaining to Google Docs were experimental [27,107]. The two other experimental studies were conducted with wikis [108,109]. As seen in Appendix 1, the types of reported outcomes varied greatly depending on the context, goal and framework used. Most outcomes concerned intermediate self-reported outcomes (e.g., self-efficacy, usability scores, user satisfaction, dialogical communication scores) and some observed process outcomes (e.g., wiki usage and contribution statistics, pre/post-test knowledge scores, quality of information, readability scores, number of communications). One study measured patient-oriented outcomes, such as blood pressure, physical activity, and cholesterol levels [107].

Use patterns of CWAs

We found a total of 26 studies that presented different patterns of CWA use in health care: who uses the different CWAs, how much, and for what reasons (Appendix 2; [29,42,53,110-130,189, 263]). Most of these studies were conducted in the United States, United Kingdom, or Australia, and 1 and 3 studies were performed in Spain and in Canada respectively. All studies were published after 2006. Study populations varied widely including health care professionals (n=12), students (n=9), consumers (n=4), teachers/educators (n=2), scholars (n=1), and librarians (n=1).

Most recurrent reasons for use were for academic purposes (case-based learning, e-learning, use of Web 2.0 tools for teaching) [110-115, 264], for clinical purposes (to support patient care, to obtain drug information, to stay updated) [53,111,116-118], for personal use (by health care professionals and students) [42,118-121] and for seeking health information [122-127] or about specific diseases [128,129]. Other reasons were to update a scoping review [130] and to seek multiple stakeholder input [100,105]. Figure 4 shows that most CWAs described involve peer-to-peer communication between health professionals, followed by CWAs used by patients and researchers respectively.

Figure 4. Medicine 2.0 Map of the different CWAs described in the included studies



In general, CWA use varied depending on the training level (e.g., 70% or 132/188 first-year medical students using Wikipedia vs 37% or 86/234 third-year medical students [124], the field of practice (e.g., 9% or 4/44 pediatric neurologists used wikis [120] vs 35% or 369/1056 pharmacists [116]), and reason for use (e.g., 100% or 51/51 radiology residents using a radiology department wiki [53] vs 15% or 360/2400 first-year psychology students using Wikipedia for personal information needs [121]). We found that a high prevalence of CWA use (i.e., more than 50%) was reported in 58% (7/12) of surveys conducted with health care professionals and students (see Appendix 2). The only longitudinal study conducted between 2005 and 2009 observed an increase in prevalence of Wikipedia use from 2% to 16% among undergraduate medical and biomedical students [123]. Another study reported higher use among younger medical students (480/593 (81%)) compared to older consultants (215/389 (55%)) [114]. Studies on the use of Wikipedia by pharmacists report

rates of use ranging between 35% using this site for work-related questions in 2009 [116] to 72% using it mainly for personal reasons in 2011 [119]. For consumers, Wikipedia was ranked first when using search engines to find information about rare diseases [125] and to find information on generic drugs [126]. Wikipedia ranked as the second most consulted website both by a group of patients with Crohn's disease [128] as well as by students searching for biomedical information [124]. While CWA rates of use are high, most reports present low rates of contributions to CWAs. From 6%-18% of students contribute to CWAs [114,115,121] while 3%-22% of junior physicians were reported to contribute to a CWA [42,264]. Furthermore, less than 1% of scholars were reported to contribute to a wiki project aiming at updating a scoping review [130]. Rarely, high rates of contribution were found in specific wiki projects [53,100].

Quality of the information in collaborative writing applications

We found 25 papers reporting on the quality of information in CWAs (Appendix 3; [54,58,61,63, 96,99,104,121,122,124,131-137,182,183,190,195-199]). With the exception of one paper evaluating the quality of information in 52 medical wikis other than Wikipedia [99], all studies focussed on evaluating the quality of medical information in Wikipedia (n=24). No studies evaluated the quality of information within projects using Google Docs; however one did compare the quality of information within Wikipedia and Google Knol [96]. Most studies (64%, 16/25) evaluated information destined to consumers while 32% (8/25) addressed the quality of information for students. Overall, 44% (11/25) of authors concluded that information within wikis and Wikipedia is partially reliable (i.e., quality of information needs to be improved or updated) while 28% (7/25) reported that information within wikis and Wikipedia is not reliable and should not be used. Three studies reported no formal conclusion about quality of information [96,121,131]. Three authors concluded that medical information in wikis and Wikipedia was reliable and of high quality [54,104,132], yet only three used a validated quality assessment instrument [99,104,133]. Of the latter, one concluded that expert-moderated wikis could produce higher quality of information [99]. For example, wikis like WikiDoc [98], ECGpedia [234] and WikiKidney [230] were among the top-rated wikis in this study [99]. However, this study also concluded that all the wikis evaluated still needed improvements mainly concerning their completeness before they could safely be used for decision making. Another study concluded that Wikipedia was adequate for clinician and student education [104] while the third study concluded that further improvement of orthognatic surgery information was needed in Wikipedia before referring consumers to the site to support decision making [133]. A recurrent finding about Wikipedia was that its content is accurate, but that it often omits important medical facts and information [58,61].

As an educational tool, Wikipedia was reported to be comprehensive, of high quality, current, and appropriate for learning in gastroenterology and pathology [54,134]. However, variability in the content, accuracy, completeness, and referencing of drug information was reported [135]. Moreover, one study reported that 171 out of 271 (63%) of students do not verify the validity of

references in Wikipedia articles [112]. While some think that Wikipedia should not be used by students as a source for referencing [135] or that it is unsuitable as a base for learning [63], others believe that its use by students need not necessarily be discouraged [136] and that it could be an informative and accurate source for education if used in combination with other learning materials [137]. Furthermore, one author considered CWAs to be excellent sources for continuing education and that they could represent the future of medical education as they allow for self-directed and supplementary education as well as for remote access [104].

Online collaborative writing applications as interventions

We identified four experimental studies in support of CWA use as educational and knowledge translation interventions (Appendix 4; [27,107-109]). Three of these studies were conducted in the field of health professions education [27,108,109] and one was in the field of secondary prevention of cardiovascular disease in patients with previous acute coronary syndrome [107]. These studies found that the use of CWAs improved 1) physical activity and blood pressure control, 2) scientific writing skills among health science students, 3) medical student self-confidence and communication skills, and 4) nursing leadership skills. One study found that CWA use worsened diagnostic skills.

Taxonomy for perceived positive and negative effects associated with CWAs

We classified the perceived positive and negative effects associated with CWAs into a taxonomy, covering eight categories (Table 2; [2,27,32,53,72,76,94,100,102,103,105,107-110,122,130,138-178,265,266]).

Table 2. Positive and negative impacts of collaborative writing applications

Impacts	Number of papers in which the impacts perceived as *positive*	Number of papers in which the impacts perceived as *negative*
Processes (intermediate outcomes)[a]		
1. Effects on psychological domains[b]	**28**	**6**
1.1 Beliefs about capabilities (Self-efficacy)[b]		
1.1.1 Self-efficacy/empowerment: Not further specified	10 [32,108,122, 138-143,163]	
1.1.2 Empowering environment	2 [109,139]	
1.1.3 Empowerment of families/relatives	1 [144]	
1.1.4 Patient participation	3 [101,103,110]	
1.2 Motivation[b]		
1.2.1 Engagement	7 [100,145-150]	

Impacts	Number of papers in which the impacts perceived as *positive*	Number of papers in which the impacts perceived as *negative*
1.3 Emotion[b]		
1.3.1 Satisfaction	5 [27,141,145, 151,152]	1 [150]
1.3.2 Loss of autonomy/feeling of being monitored		1 [32]
1.3.3 Feeling of working in isolation		1 [153]
1.3.4 Feeling of guilt about not participating		1 [109]
1.3.5 Frustration due to technical issues		1 [154]
1.3.6 Added stress		1 [155]
2. Learning effects	**30**	**1**
2.1 Subjective learning improvements: Not further specified	9 [108,114,140, 141,145,150, 152,156,157]	
2.2 Skills[b]		
2.2.1 Communication skills e.g. feedback	2 [138,151]	
2.2.2 Handle fears and feelings	1 [158]	
2.2.3 Adapt to different learning styles	4 [72,109, 141,142]	
2.2.4 information and communication technology skills	1 [154]	
2.2.5 Transfer of knowledge into practice	1 [138]	
2.2.6 More efficient critiquing and evaluating the medical literature	1 [138]	
2.2.7 Development of professionalism on students	1 [32]	
2.2.8 Enhanced understanding of concepts	1 [159]	
2.2.9 Decreased learning of diagnostic skills		1 [108]
2.3 Knowledge[b]		
2.3.1 Knowledge (not further specified)	4 [72,109, 154,160]	
2.3.2 Awareness of guidelines	1 [161]	
2.5 Better supervision by teachers	2 [141,154]	
2.6 Better exam preparation	2 [108,110]	
3. Communication	**24**	**2**
3.1 Communication: Not further specified (impedes/improves)	9 [27,32,76, 108,148,153, 162-164]	2 [109,141]
3.2 Feedback	2 [151,165]	
3.3 Collegiality	1 [159]	
3.4 Patient/health professionals communication	2 [144,146]	
3.5 Communication of tacit knowledge[b]	3 [76,163,164]	
3.6 Creates a network for families	1 [144]	
3.7 Apomediation (communication process whereby individuals "stand by" to guide consumers to high quality information without being a prerequisite to obtain that information in the first place) [b]	1 [164]	

Impacts	Number of papers in which the impacts perceived as *positive*	Number of papers in which the impacts perceived as *negative*
3.8 Dialogical communication between organizations and individuals[b]		
3.8.1 Mutuality (the recognition of organization–public relationships)[b]	1 [122]	
3.8.2 Propinquity (the temporality and spontaneity of interactions with publics)[b]	1 [122]	
3.8.3 Empathy (the supportiveness and confirmation of public goals and interests)[b]	1 [122]	
3.8.4 Risk (the willingness to interact with individuals and publics on their own terms)[b]	1 [122]	
3.8.5 Commitment (the extent to which an organization gives itself over to dialogue, interpretation, and understanding in its interactions with publics)[b]	1 [122]	
4. Collaboration	**41**	**4**
4.1 Collaboration: Not further specified (impedes/improves)	23 [72,76,100, 102,110,138-143,145-148, 151,154,161, 162,166-169]	1 [141]
4.2 Reduces geographical barriers	11 [76,100,138, 144,153,154, 160,162,163, 166,170]	
4.3 Perceived unequal/equal separation of work	3 [100,110,141]	2 [141,154]
4.4 Asynchronous communication	1 [163]	
4.5 Wiki used as a conversational manner without contributing to the same text		1 [141]
4.6 Define team responsibilities	1 [156]	
4.7 Interprofessional collaboration	1 [105]	
4.8 Creation of online presence	1 [156]	
5. Knowledge management and accessibility to information	**30**	**14**
5.1 Dissemination of information	8 [110,163,164, 167,169,171-173]	
5.2 Fast dissemination of poorly validated information		4 [102,159, 164,174]
5.3 Better access to information	8 [138,140,152, 163,169,171, 175,176]	
5.4 Better exposure to world	1 [168]	
5.5 Better knowledge translation across organizations	2 [146,164]	
5.6 Centralized knowledge management	5 [140,152,156, 164,166]	1 [110]
5.7 Constantly updated information	1 [169]	

Impacts	Number of papers in which the impacts perceived as *positive*	Number of papers in which the impacts perceived as *negative*
5.8 Facilitates management of various content	1 [172]	
5.9 Privacy issues health related data		1 [146]
5.10 Spam/vandalism		2 [130,177]
5.11 Updating of knowledge synthesis		1 [130]
5.12 Saves paper	1 [175]	
5.13 Information overload		4 [109,164, 175,176]
5.14 Wiki allows daily surveillance (looking for spurious edits)	1 [53]	
5.15 Compiling anonymous data	1 [144]	
5.16 Creativity/new ideas	1 [110]	
5.17 Editing wars		1 [167]
Outcomes		
6. Efficiency of health care	**19**	**4**
6.1 Efficiency: Not further specified	5 [72,110,146, 151,166]	2 [141,164]
6.2 Saves money	1 [166]	
6.3 Saves time/loses time	11 [32,102,146, 148,152,155, 161,163,166, 169,170]	1 [162]
6.4 Decreases/increases duplicate work	1 [164]	1 [155]
6.5 Reduces workload	1 [174]	
7. Quality Improvements	**6**	**2**
7.1 Quality Improvements: Not further specified	5 [27,144,146, 151,166]	1 [164]
7.2 Wiki content didn't meet users' needs		1 [178]
7.3 Reduces errors	1 [155]	
8. Disease prevention	**3** [107,142,146]	

[a] The Donabedian framework [93] for quality improvement was used to describe processes and outcomes.

[b] These items are processes that were taken from other psychological and organizational frameworks for change and used to describe and classify the effects of CWAs found in this review [2,94,265,266].

In total, 57 positive effects and 23 negative effects were identified. Among the categories of positive effects that we found, the most frequently reported were that CWAs improve collaboration (n=41), positively impact learning (n=30), influence psychological domains (n=28), facilitate knowledge management and accessibility to information (n=30), improve efficiency of health care (n=19), improve quality of health care (n=6), and prevent disease (n=3). Among these effects, the Theoretical Domains Framework [94] was used to label and classify 22 of them into 3 psychological domains (self-efficacy, motivation, emotion) and 2 learning effects (skills and knowledge).

We found 2 studies referring to theoretical frameworks to describe their effects. Among the frameworks, the concept of communities of practice [266] was used to classify 3 studies reporting that CWAs improved the communication of tacit knowledge. The Dialogic Theory of Public Relations [265] was used to describe 5 positive effects wikis could have on public relations between health care organizations and consumers.

The most frequently cited negative effects were that CWAs could have unfavorable impacts on knowledge management (n=14) such as information overload (n=4) and fast dissemination of poorly validated information (n=4), as well as on certain psychological domains (n=6) such as added stress (n=1) and negative emotions (n=5). Some authors stated that CWAs could impede certain aspects of collaborative work (n=4) such as enhancing the perception of unequal work distribution (n=2) and encouraging conversation more than collaborative writing (n=1). Potentially serious negative effects of deletion of important medication information on Wikipedia by pharmaceutical companies (n=1) [177] and breaching of patient confidentiality (n=1) [179] were reported only in the grey literature.

Taxonomy for barriers and facilitators to the use of CWAs in health care

A total of 48 barriers and 91 facilitators to the use of CWAs in health care were identified, of which 20 barriers and 69 facilitators were new determinants (Table 3; [32,53,54,76,100-102,106,109, 110,114,116,130,141-143,145-149,153-156,159,162-164,166-174,176,178,180,181, 267-271]).

Table 3. Barriers and facilitators related to the use of collaborative writing applications

Factors (Gagnon et al 2012 taxonomy)	Number of papers in which the factor was mentioned as a facilitator	Number of papers in which the factor was mentioned as a barrier
1. Factors related to ICT (CWA)		
1.1 Design and technical concerns	**13**	**8**
1.1.1 Readability of the information[a]		1 [171]
1.1.2 Appearance of wiki (font, etc.)[b]	1 [101]	1 [159]
1.1.3 Organization of information[b]	5 [101,163, 169,171,180]	
1.1.4 Immediately available technical information[a]	1 [166]	
1.1.5 Having a sense of continuity and stability[b] *[267]*	1 [109]	
1.1.6 References not intrusive in lay language texts[a]	1 [167]	
1.1.7 Information overload [a]		2 [109,170]
1.1.8 Mobile access[b]	1 [155]	
1.1.9 Spam filter[a]	1 [130]	
1.1.10 System can improve[a]	1 [154]	
1.1.11 Rapid information changes[b]	1 [155]	1 [130]
1.1.12 Design and technical concern – other		3 [109,142,154]
1.2 Characteristics of the innovation	**28**	**5**
1.2.1 Ease of use/complexity		
1.2.1.1 Ease of content editing[a]	6 [106,163, 166,170,176,180]	
1.2.1.2 Human/computer interactions[b]		
1.2.1.2.1 Consistency (principle of minimum amazement)[b] *[268]*	1 [109]	
1.2.1.2.2 Prevent error messages[b] *[268]*	1 [109]	
1.2.1.2.3 Temporal contiguity (easy mental associations are made between verbal and visual)[b]	1 [109]	
1.2.1.3 Reduce Short-Term Memory Load [b]*[268]*	1 [109]	
1.2.1.4 Ease of use/complexity – other	8 [100,109, 110,141,146, 147,164,166]	4 [109,141,153,172]
1.2.2 Triability		
1.2.2.1 *Permit Easy Reversal of Actions*[b] [183]	3 [106,109,169]	
1.2.2.2 Triability – other	7 [32,102,109, 153,154,156,172]	
1.2.3 Relative advantage (usefulness) or lack of		1 [130]
1.3 System reliability	**2** [109,169]	
1.4 Interoperability (including web browser interoperability)	**3** [53,146,169]	**2** [154,178]

Factors (Gagnon et al 2012 taxonomy)	Number of papers in which the factor was mentioned as a facilitator	Number of papers in which the factor was mentioned as a barrier
1.5 Legal issues	**2**	**6**
1.5.1 Confidentiality – privacy concerns	2 [153,163]	3 [32,109,170]
1.5.2 Liability[a]		1 [172]
1.5.3 Copyright concerns[a]		2 [170,172]
1.6 Validity of the resources	**16**	**9**
1.6.1 Scientific quality of the information resources	10 [32,102,142, 153,155,159, 163,169,170,174]	5 [114,130,171, 172,176]
1.6.2 Content available (completeness)	2 [169,174]	2 [54,178]
1.6.3 Appropriate for the users (relevance)	2 [53,176]	1 [178]
1.6.4 Content updated frequently[a]		1 [54]
1.6.5 Highly prevalent disease[a]	1 [130]	
1.6.6 Rapidly growing body of research[a]	1 [130]	
1.7 Cost issues: low human and hardware costs	**3** [53,146,169]	**2** [146,166]
1.8 Social aspects of ICT[a]	**28**	**7**
1.8.1 Integrated support tools within wiki (toolbox, FAQ, forum, policies)[b]	6 [149,153,163, 164,167,169]	
1.8.2 Open access wiki[b]	1 [53]	5 [109,155,163, 169,173]
1.8.3 Good balance between restricted areas within wiki (private info) vs open areas (info for all)[a]	2 [106,130]	
1.8.4 Interface linking content to conversations[b]	2 [109,180]	
1.8.5 Use of template and seed with core set of pages[a]	4 [163,164, 167,169]	
1.8.6 Webmetric tool integrated with ICT to measure use (e.g. Google Analytics) and contributions/authorship (e.g. Wikigenes)[a]	1 [130]	
1.8.7 Simultaneous real-time collaborative editing[a]	1 [109]	
1.8.8 Gives informative feedback[b]*[268]*	1 [109]	
1.8.9 Authorship transparent to increase reliability[a]	3 [130,169,174]	
1.8.10 Socialization tactics (e.g. welcome message)[a]	1 [130]	
1.8.11 Controversial content[a]	1 [130]	
1.8.12 Important impact on a large number of health professionals[a]	1 [130]	
1.8.13 Lack of interest in topic[a]		1 [130]
1.8.14 Wiki enabled with an RSS feed or email notifications (reminders)[b]	4 [32,109, 159,163]	
1.8.15 Inappropriate automatic computer editing[a]		1 [154]

Factors (Gagnon et al 2012 taxonomy)	Number of papers in which the factor was mentioned as a facilitator	Number of papers in which the factor was mentioned as a barrier
2. Individual factors or health care professionals characteristics (knowledge and attitude)		
2.1 Knowledge	**1**	**12**
2.1.1 Awareness of the existence and/or objectives of the ICT		2 [130,141]
2.1.2 Familiarity with ICT		
2.1.2.1 Skills[b] [269]	1 [109]	
2.1.2.2 Familiarity with ICT – other		8 [109,114,116,130, 148,153,168, 181]
2.1.3 Lack of proficiency in English (the language of the Web)[a]		1 [146]
2.1.4 Lack of knowledge about systematic review methods[a]		1 [130]
2.2 Attitude	**17**	**18**
2.2.1 Agreement with the particular ICT		
2.2.1.1 Challenge to autonomy		1 [50]
2.2.1.2 Outcome expectancy (use of the ICT leads to desired outcome)	1 [130]	
2.2.1.3 Motivation to use the ICT (readiness)/resistance to use the ICT		4 [109,140,147,149]
2.2.1.4 Motivation to contribute to the wiki (desire to participate and post messages/information)[b] [269]	3 [109,156,174]	1 [130]
2.2.1.4.1 Motivation to contribute needs to be consistent with the person's goals, plans, values, beliefs and interests[b] [269]	2 [109,156]	1 [130]
2.2.1.5 Self-efficacy (believes in one's competence to use the ICT)	6 [109,130,141, 145,153,168]	6 [32,114,142, 153,170,178]
2.2.1.6 Preference for private learning environment compared to open environment [a]	2 [32,162]	
2.2.1.7 Impact on personal life[b] [267]	1 [109]	
2.2.1.8 Confidence in ICT developer		1 [116]
2.2.1.9 Agreement with the particular ICT – other	1 [178]	2 [156,170]
2.2.2 Agreement with ICTs in general (welcoming/resistant)	1 [174]	2 [114,168]
3. Human environment		
3.1 Factors associated with patients	**3**	**0**
3.1.1 Patient/health professionals interaction		
3.1.1.1 Sharing of information between doctors and patients[a]	1 [174]	
3.1.1.2 Sharing of information between doctors[a]	1 [174]	
3.1.1.3 Sharing of information between patients[a]	1 [174]	
3.2 Factors associated with peers	**25**	**7**
3.2.1 Support and promotion of ICT by colleagues		
3.2.1.1 Support by nurses[b]	1 [155]	
3.2.1.2 Support by physicians[b]	1 [155]	

Factors (Gagnon et al 2012 taxonomy)	Number of papers in which the factor was mentioned as a facilitator	Number of papers in which the factor was mentioned as a barrier
3.2.1.3 Support by trainees[b]	1 [155]	
3.2.1.4 Support and promotion by colleagues (not further specified)	3 [109,153,171]	
3.2.2 Other factors associated with peers (relations between colleagues)		
3.2.2.1 Credential verification[a]		1 [102]
3.2.2.2 Frustration about having someone else edit personal contribution[b]		3 [106,109,141]
3.2.2.3 Reluctance to team work[b]		3 [141,154,156]
3.2.2.4 Using constructivist theoretical framework to setup a wiki is helpful[b] *[270]*	3 [109,153,156]	
3.2.2.5 Presence of a community of practice/community of learners[b]		
3.2.2.5.1 Critical mass of scholar[a]*s*	1 [130]	
3.2.2.5.2 Presence of a small group of motivated editors[a]	1 [130]	
3.2.2.5.3 Presence of community of practice/ community of learners (not further specified)[b]	7 [76,106,109, 149,156, 169,174]	
3.2.2.6 Openness, trust and respect[b]	4 [106,109, 130,163]	
3.2.2.7 Need for reciprocity (questions answered)[b]	2 [109,156]	
3.2.2.8 Create teams of two collaborators working on same wiki page[a]	1 [162]	
4. Organizational environment		
4.1 Internal environment	**69**	**27**
4.1.1 Work (nature of work)		
4.1.1.1 Time constraints and workload		
4.1.1.1.1 Ultra-rapid decision making environment[b]		1 [155]
4.1.1.1.2 Time constraints and workload – other	1 [32]	6 [109,114,141, 148,162,170]
4.1.2 Resources availability		
4.1.2.1 Resources available (additional)		1 [116]
4.1.2.2 Material resources (access to ICT)		
4.1.2.2.1 Lack of constant Internet connection/access[b]		2 [146,155]
4.1.2.2.1.2 Material resources (access to ICT) – other	6 [106,109,141, 153,166,180]	5 [114,146,153, 154,178]
4.1.2.3 Human resources (IT support)	4 [109,154, 156,171]	1 [146]
4.1.2.4 Having a single platform[a]	1 [162]	

Factors (Gagnon et al 2012 taxonomy)	Number of papers in which the factor was mentioned as a facilitator	Number of papers in which the factor was mentioned as a barrier
4.1.3 Organizational factors		
4.1.3.1 Training		
4.1.3.1.1 Face-to-face training[b]	6 [32,76,141, 149,153,156]	
4.1.3.1.2 Use smaller groups (n=15-20) for one on one feedback[b]	1 [109]	
4.1.3.1.3 Educators must be aware of human-computer interactions[b]	1 [109]	
4.1.3.1.4 Training medical educators in using Web 2.0 ICTs[a]	1 [114]	
4.1.3.1.5 Need for active learning/constructivist learning[b]		1 [109]
4.1.3.1.6 Training – other	12 [53,76,109, 141,143,145, 148,153,154, 159,163,169]	1 [146]
4.1.3.2 Management (strategic plan to implementing applications)		
4.1.3.2.1 Start with pilot project (implementation strategy)[a]	1 [162]	
4.1.3.2.2 Index with Google – use Google Adwords (implementation strategy)[a]	1 [167]	
4.1.3.2.3 Monitoring of use with Web metrics[b]	3 [130,156,167]	
4.1.3.2.4 Management – other		2 [109,141]
4.1.3.3 Presence and use of "champions"	1 [54]	
4.1.3.4 Participation of end-users in the design	1 [172]	
4.1.3.5 Communication (includes promotional activities)		
4.1.3.5.1 Work with computer science department to implement a plan to generate traffic to wiki[a]	1 [167]	
4.1.3.5.2 Getting new staff to participate for new look[a]	1 [163]	
4.1.3.5.3 Encourage writers to contribute using their own style[a]	1 [163]	
4.1.3.5.4 Forcing students to edit wiki[a]	1 [130]	
4.1.3.5.5 Participating in a community of wiki editors[a]	1 [130]	
4.1.3.5.6 Communication – other	3 [130,154,167]	
4.1.3.6 Ongoing administrative/organizational support		
4.1.3.6.1 Interactive Web applications permitted and unblocked within the health care institution[b]	1 [109]	
4.1.3.6.2 Administrative/ organizational support – other	3 [109,130,156]	1 [114]

Factors (Gagnon et al 2012 taxonomy)	Number of papers in which the factor was mentioned as a facilitator	Number of papers in which the factor was mentioned as a barrier
4.1.3.7 Incentive structures		
4.1.3.7.1 Giving continuing medical education (CME) credit[a]	1 [130]	
4.1.3.7.2 New set of scholarly impact metrics[a]	1 [130]	
4.1.3.7.3 Major cultural barrier in academia against participating in social media[a]		1 [130]
4.1.3.7.4 Incentive structures – other	5 [54,102, 109,162,169]	2 [130,172]
4.1.3.8 Presence of a moderator[b]	7 [53,102,109, 153,156,167, 172]	
4.1.3.9 Presence of metacognitive participants and dialogical participants[b] *[271]*	2 [109,156]	
4.1.3.10 Accept that not all will participate and that lurkers will always exists/frustration about the lurkers who don't contribute[b]	1 [109]	3 [141,149,154]
4.2 External environment	1	1
4.2.1 Financing of ICT/financial support		1 [109]
4.2.2 Coupling traditional publications with wiki contributions[a]	1 [130]	

[a] These new determinants did not exist in the Gagnon et al framework.
[b] These new determinants were identified in papers using a theoretical framework.

Among the latter, some were specific to social media (e.g., social aspects of ICT, presence of a moderator, presence of a community of practice) and others were not (e.g., information overload, mobile access, lack of proficiency in English). Although we found only 5 studies [101,109,153,155,156] that used a theoretical framework to identify barriers and facilitators, many of these barriers (n=11) and facilitators (n=34) were among those deemed as new.

The five barriers most frequently mentioned, in order of frequency, were unfamiliarity with ICTs (n=8), time constraints and workload (n=6), lack of self-efficacy (belief in one's competence to use ICT) (n=6), material resources – access to ICT (n=5), worries about the scientific quality of the information (n=5), and the presence of a closed wiki protected by a password (n=5). The five most recurrent facilitators were having had training (n=12), scientific quality of the information (n=10), ease of use (n=8), triability (n=7), presence of a community of practice or a community of learners (n=7) and presence of a moderator (n=7).

Discussion

Principal findings

We confirmed that CWAs are currently being used frequently in health care, by a variety of stakeholders including patients, professionals, and researchers, for a large diversity of purposes. Our complete portrait of the literature shows that wikis are by far the most commonly studied type of CWA and that most studies had observational designs. Each type of CWA has different collaborative writing and conversational features that must be considered by decision makers when making a choice about which CWA to use in different collaborative projects. Many positive effects are attributed to the use of CWA in health professions education and knowledge translation. Further systematic synthesis of experimental and quasi-experimental evidence is needed before any clear policy recommendations can be made about implementing these tools in current practice. Moreover, there is an array of potential negative effects and barriers that need to be addressed in future primary research projects.

The use of CWAs in health care

Despite the controversy surrounding the use of information in Wikipedia in clinical decision making [57,65], a high proportion of health professionals and students are already using Wikipedia and other CWAs, with use apparently increasing especially among younger professionals. Although more research is needed to confirm this trend, these findings are consistent with an overall trend to increased use of social media among health professionals [79,272]. Our systematic mapping of the literature shows that wikis are the most frequently studied type of CWA. Furthermore, the use of Wikipedia by students and professionals represents the focus of many of our included studies. Google Docs studies come second, and we found only one study about Google Knol. This is not surprising since Wikipedia is the sixth most visited website worldwide and appears in top 10 results of search engines concerning health questions [125]. However, as readership of Wikipedia is rapidly changing, it is important to acknowledge that usage percentages depend not only on how you ask the question but also when you ask the question Moreover, Google terminated the Knol project in 2011 despite interesting health projects using this platform including the PLoS Currents: Influenza project [273,274]. Besides the single publication we found about Google Knol comparing Knol to Wikipedia [96], there are no published accounts of Google's reasons for closing and transferring Knol to the Annotum platform.

Based on the Medicine 2.0 map [2], we demonstrated that current CWAs in use are mainly oriented towards health students and professionals' peer-to-peer interactions. In fact, use of CWAs is a major area of research in health education [275,276]. In particular, of the 4 experimental studies identified, 3 were education studies showing that CWAs positively influenced learning processes and almost half (n=48) of all the studies in this review concerned health professions education. Albeit less common, there are also studies about CWAs involving consumers and professionals to co-create decision-making tools [100,101,105,277]. These four projects seem relevant given that patient-centered care has become a central aspect of KT and

experts have called for new ways of involving patients in the implementation of evidence [278]. Another remarkable finding is that even fewer CWAs involve consumers and researchers in sharing hard to find phenotype information about rare genetic and congenital diseases [104,143].

Researchers are starting to explore the use of CWAs, for example in updating a scoping review [130]. Another expert/researcher driven wiki is the OpenMRS electronic medical record implementation wiki, an example of wikis' full potential for improving health in developing countries. Although the World Health Organization is exploring the use of a wiki to update the 11th International Classification of Disease [49], we did not find any published accounts on their experience, nor did we find any related to the discontinuation of Medpedia [37]. The reasons for ending this ambitious project involving important stakeholders would provide lessons for the future.

CWAs features and implications for health care

After comparing how each CWA was used in different collaborative writing projects, we found that wikis and certain hybrid custom-built wikis have collaborative writing features that are more prominent compared to their conversational features. These collaborative writing features produce artefacts of synthesized knowledge that lend themselves more readily to daily use than those produced from conversational knowledge. For example, using a wiki to store and update care protocols readily applicable to the care of emergency department patients would be more useful in daily practice than reading the discussion page found in support of the wiki page itself. Conversely, Google Docs, certain knowledge management applications (e.g., Google Sites, Microsoft SharePoint) and other social media platforms (e.g., MijnZorgNet, Atlassian Confluence, MinJournal) integrate additional features that favor conversation and deliberation between users. These additional conversational features produce discussions between users about the knowledge being shared and add to users' understanding about the content found on the collaborative writing pages of these applications.

Effects of CWA and wiki use in health care

Most evidence stemmed from case reports and observational studies demonstrating perceived positive effects of CWA use in health care on behavior change, education, communication, collaboration, knowledge management and access to knowledge, and better quality and efficiency of health care. These findings support claims that CWAs and wikis facilitate that online professional communities create, share, and synthesize knowledge; increase access to health information; and offer opportunity for public participation and citizenship [84,276,279]. Although less frequently reported, we also found a series of perceived negative effects (i.e., information overload, fast dissemination of poorly validated information, loss of autonomy, feeling of working in isolation, increased stress, perceived unequal distribution of tasks within teams, biased editing, editing wars, and vandalism/wikispam) that could mask some of the positive effects of CWAs. Innovative developments such as semantic wikis [8,97,98,276,280] and bots [11,281] may

decrease some of these negative effects. For example, to reduce the impression of information overload, certain authors are exploring semantic wikis to better organize and structure information based on a logical ontology [97,98]. Semantic wikis could help organize the knowledge being shared [8,276,280], potentially improve its meaningful use [282,283] and eventually allow its integration into intelligent Web-based decision-support tools [280]. Other authors are exploring the use of bots to decrease the risk of vandalism, biased editing, and spam [11,281]. A bot is a computer program that runs automatically and continuously within wikis and can conduct simple tasks like correcting spelling and syntax. Wikipedia contains many different bots that help ensure its quality [281]. More complex bots exist like the one in WikiPathways that surveys the content and identifies potential inconsistencies, redundancies, and incomplete data [11].

Barriers and facilitators to the use of CWAs and wikis in health care

The use of CWAs in health care faces barriers that limit their use that are similar to those experienced in other fields: unfamiliarity with ICT [284], time constraints and workload [275], lack of self-efficacy to use CWAs [275], access to CWAs [285], worries about the scientific quality of the information resources [276,281,286,287], readability of information [281], the presence of a closed wiki protected by a password [276,281] and legal concerns [276,286,287].

A recurrent finding about the information in Wikipedia was that it is in large part accurate, free, and easy to access. However, even though Wikipedia does not recommend including medication doses due to concerns about errors [288], it is often incomplete and can lack appropriate referencing of medical information [58,61] thereby possibly indirectly causing patient harm [135]. One observational study demonstrated that involving moderators and experts in the sharing and curation of information within CWAs improves the quality of information [99]. However, as previous authors have demonstrated, finding ways to get these experts to participate remains a challenge [4,130,182,276,289].

Maintaining high-quality information as well as high contribution levels is a heated debate with opposing views (i.e., password-protected wiki vs open wiki) [53,105,109,155,163,169,173]. Authors from multiple fields have explored modalities to stimulate participation [276,281,284,285,290-296]. Many facilitators reported from fields other than health care include training [284,296], scientific quality of the information resources [281,286,287], ease of use [291], having access to integrated support tools [296], ease of content editing [297-299], access to CWA [285], self-efficacy [300,301] and the use of incentives [293,294,302-304]. Some propose a set of scholarly metrics that would reward contributions to collaborative projects [130]. The journal *RNA Biology* stimulates contributions to Wikipedia by scholars by requiring that manuscripts be summarized for a Wikipedia page before accepting to publish the article [305]. The WikiGenes project has recognized the importance of authorship [10,36]. Finally, similar to other fields [293,294,297,306], the presence of a community and the sense of community is a frequently reported facilitators that increase contributions by health care stakeholders. Experts suggest that

studying CWAs involves looking at both the technology and its community of users [276,285,307]. Thus, understanding the success of a project using a CWA must also include exploring the fundamental elements of communities of practice [266]. Communities of practice can meet online (i.e., virtual community) or face to face. Similar to systematic reviews on communities of practice [308,309], our scoping review identified the presence of a moderator and/or a champion as a key factor for a successful collaborative writing project. Related to the concept of community, the success of a collaborative writing project also includes having a critical mass of participants, shared values, openness, trust, and respect.

Clinical relevance

We believe that our findings are important for consumers, professionals, researchers, and health care organizations around the world that are already using CWAs and/or planning to use a CWA to improve health care. Although we have found some evidence from experimental studies to support the use of CWAs as a health profession's educational intervention and a large body of observational evidence supporting the use of CWAs as a knowledge translation intervention, a formal systematic review should be conducted to further synthesize the evidence and conduct a formal risk of bias assessment before making practice recommendations. Furthermore, the implementation of CWAs is fraught with barriers and the potential for adverse effects, requiring primary research to assess their safety.

Unfortunately, the breadth and depth of the literature on the use of CWAs specific to public health is scarce. However, based on some ongoing and promising projects [49,76,99,139,146,164], it is clear that the uses of CWAs for public health are vast and far-reaching. Although more research is needed within this specific domain, CWAs improve information access, collaboration, and can improve health education – all tenets of public health. Patients and consumers often experience many barriers in the use of CWAs, with information quality being among the most reported. The readability of articles within Wikipedia is a key area that must be addressed, as it will improve health literacy and knowledge translation [310]. There are also promising projects that may shed light on the effectiveness of involving patients in the development of clinical of guidelines [311]. Evidence from experimental studies about engaging patients with CWAs is still rare and needs to be replicated in robust prospective trials before making recommendations.

Strengths of this study

This is the first study that has conducted a scoping review to examine the depth and breadth of evidence about the use of CWAs in health care. We rigorously followed scoping review methodology and conducted a systematic and broad search of CWA use in multiple scientific databases and grey literature sources. A scoping review was the ideal methodology to employ for a number of reasons. First, it is an explorative method used when the relevant literature is considered to be broad and diverse [312]. Moreover, the study of these applications is an emerging field that is being examined with diverse methods [28,32,61], with different theoretical

frameworks [29] and in different contexts [46,313]. We used a high-quality collaborative Web-based software to manage our review, to import studies, to extract data and to create reports. Every step of our review has been extensively described. By including knowledge users and policy makers, we have produced a relevant synthesis of the evidence targeting their needs. Based on empirical results, this scoping review has also extended an existing taxonomy of adoption determinants to the study of a social media application. The original taxonomy had been developed using a rigorous mixed-methods systematic review methodology [78]. Although our new extended taxonomy is very comprehensive, we believe that this level of detail was important to maintain in order to help future researchers explore the impact of these barriers and facilitators. Moreover, we have also created a new taxonomy of effects based on elements from other sociocognitive and organizational frameworks of change. Our use of the Donebadian framework was very useful because of its generalizability and overarching broad scope. Other more specific frameworks (e.g., Theoretical Domains Framework) fit well within this overarching framework. Research should validate our two taxonomies for future development, assessment, and implementation of other social media applications.

Limitations of this study

Even though we did everything possible to minimize publication bias by systematically and extensively searching for any sources of the grey literature presenting negative results (e.g., including a lay media newspaper article [177]), we believe publication bias is not excluded. For example, we have not found published reports explaining the failed attempts at maintaining Google Knol or Medpedia. Many other CWAs sites have also disappeared over the course of the years without any clear explanations. In 2009, David Rothman had listed 69 medical wikis, many of which are now inactive or simply do not exist anymore [39]. Such reports describing the reasons for CWA failure would help generate important lessons for the advance of the science of collaborative writing. Second, our scoping review methodology [87,88] did not include formal quality assessment. However, we classified studies based on the strength of their design in order to help us identify areas for primary research and those that produced sufficiently robust evidence for making recommendations. Third, our scoping review was limited to reviewing CWAs using a definition that excluded related applications like blogs, microblogs, discussion forums, and patient communities (e.g., PatientsLikeMe). Even though these social media applications are collaborative as well and share some common features with CWAs, we believe that it is important to study them separately to better understand each application's impact and interaction with other social media. Finally, our search strategy is limited to studies published between January 1, 2001, and September 16, 2011, while several more recent studies about CWAs have been published [263,272,314-319].

Unanswered questions and future research

This scoping review has identified a number of research gaps. There is a need to conduct systematic reviews to further synthesize the results of experimental and quasi-experimental studies in the field of health professions education and to further synthesize evidence about implementation strategies addressing the different barriers identified. Given that the majority of the literature presently exists in the form of case reports with self-reported measurements, it is essential that further prospective trials with objective outcomes be conducted. Future trials should identify implementation processes that can be influenced by CWAs and how to measure them (possibly using Web metrics [130,167,276]) as intermediate outcomes of a complex knowledge translation intervention. In this respect, in addition to other frameworks defining evaluation plans of dynamic collaborative applications [320], our taxonomies of CWA adoption determinants and effects will help plan such trials. This will help researchers understand the different mechanisms of action at play leading to improved patient-oriented outcomes (quality of life, morbidity, mortality). Although the feasibility of conducting a randomized clinical trial to study the effectiveness of CWAs seems daunting, other complex interventions have been studied using this methodology [239].

Before conducting such trials, researchers and decision makers must reflect on defining the purpose of using a CWA as a knowledge translation intervention. Researchers must also find ways to adapt CWAs to the particular needs of different stakeholder groups (consumers, professionals, and researchers). Important barriers such as the quality of information contained in different wikis must be better addressed. As previous authors have stated [183,320], measuring the quality of user-generated content and its change over time is a challenging task requiring research [322]. Finding ways of assuring the scientific integrity of evidence within CWAs and recognizing authorship are significant stumbling blocks that need to be addressed for health care [102,114,130,171,176,323]. Studying each specific behavior involved in using CWAs (i.e., to use, to contribute, to edit, to delete) with the help of theoretical frameworks will also help inform future interventions. In addition to other technical considerations [324,325], future studies should explore the impact of collaborative writing and conversational features on information sharing and investigate what kind of knowledge (explicit vs tacit [266]) is shared. This could help knowledge users choose an appropriate CWA. As future communication tools, the impact of using different types of media embedded within CWAs (audio and video recordings) should also be explored. Finally, an important consideration to explore in future studies would be to determine the impact of using a closed vs an open CWA on the quality of the information found within the CWA and on the type of barriers experienced by users.

Conclusion

The prevalence of CWA use is high in various fields of health care, and they are used for a variety of purposes. They present many potential positive and negative effects as knowledge translation tools. Although we found some experimental and quasi-experimental evidence in favor of using CWAs as educational and knowledge translation interventions, the vast majority of included studies were observational case reports about CWAs being used by health professionals and patients. More research is needed to determine which stakeholders benefit the most from using CWAs, to address the barriers to their use, to find ways to ensure the quality of their content, to foster contributions, and to make these tools effective knowledge translation tools for different stakeholders. Answers to these questions are needed before clear policy recommendations can be made about the safe use of CWAs in health care.

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Appendices

Appendix 1. Characteristics of included studies
Appendix 2. Patterns of use of collaborative writing application
Appendix 3. Quality of information in collaborative writing projects
Appendix 4. Characteristics and results of experimental studies

Appendix 1. Characteristics of included studies

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
1	Alkhateeb (2011) [119]	Survey	Wiki (Wikipedia)
1	Archambault (2010) (G, A) [29]	Case study	Google docs
1, 3	Bender (2011) (G) [130]	Case study	Wiki (Open Medicine wiki http://wikisr.openmedicine.ca) [261]
1,3	Brokowski (2009) [116]	Survey	Wiki (Wikipedia)
1	Dodson (2011) [111]	Survey	Wiki
1	Gonzalez de Dios (2011) [120]	Survey	Wiki and Google Docs
1, 3	Gupta (2010) (A) [100]	Case study	Hybrid wiki (Wikibreathe/OCTAPUS tool: http://knowledgetranslation.ca/octapus/login.php)
1	Harris (2010) [112]	Survey	Wiki (Wikipedia)
1,2,3	Hickerson (2009) (G) [122]	Survey	Wiki (Wikipedia; WikiHealth (www.wikihealth.com) [260])
1, 3	Hughes (2009) (G) [42]	Survey	Wiki (Wikipedia)
1	Iyer (2011) (D) [117]	Survey	Wiki (Wikipedia)
1	Judd (2010) [123]	Observational analytic design	Wiki (Wikipedia)
1, 2	Judd (2011) [124]	Observational analytic design	Wiki (Wikipedia)
1, 3	Kohli (2011) [53]	Survey	Wiki (IU Radiology: www.indyradres.org) [84]
1	Laurent (2009) [125]	Observational analytic design	Wiki (Wikipedia)

Software used	Context of study	Speciality	Type of outcomes reported
MediaWiki	Describe social media use among pharmacists in West Virginia	Pharmacy	Prevalence of use of different social media
Google Docs	Describe the use of a Google Docs slideshow	Emergency medicine	Frequency of use
MediaWiki	Updating of a scoping review	Asynchronous telehealth	Usage statistics and comments from users
MediaWiki	Pharmacists using Wikipedia for medication information	Pharmacy	Prevalence of Wikipedia use and reason for use
PmWiki (http:// www.pmwiki.org) [185], b2evolution (http:// b2evolution.net) [186] and Libguides (http:// libguides.com) [187]	Survey of health sciences libraries usage of blogs and wikis	Medical education, health care library science	Departments using wikis; type of wiki and content management software used; purposes of using wikis; description of their use of wikis and best practices reported
N/A	Survey of Web 2.0 resources used by clinicians in Spain	Paediatric neurology	Prevalence of use of different social media applications
Custom-built application***	Development of an asthma action plan	Respirology	System Usability Scale; wiki usage statistics; overall satisfaction
MediaWiki	To examine student approaches to using Wikipedia as a reputable resource	Mental health	Prevalence of use
MediaWiki****	Investigation of how wikis facilitate dialogue between consumers and health care organizations	Public relations	Measured levels of perceived dialogical communication scores
MediaWiki	Junior physicians use of Web 2.0 resources	10 different specialties	Opinion of junior physicians about using wikis
MediaWiki	Drug information-seeking behaviors among health care professionals	Pharmacy	Wikipedia usage statistics
MediaWiki	Biomedical students' on-campus use of Internet	Health care Education	Most frequented web sites and technologies
MediaWiki	Determine how undergraduate medical students used five popular sites to locate and access biomedical resources	Medical Education	Internet usage logs; students' perceptions of each site's usefulness and reliability
Dokuwiki (www.dokuwiki.org) [249]	Centralized knowledge management system to share useful documents for radiology residents (e.g., dictation templates, phone numbers, etc.)	Radiology, residency training	Resident acceptance survey
MediaWiki	Determine the significance of English Wikipedia as a source of online health information	General health information	Wikipedia's ranking on general Internet search engines; cumulative incidence and average position of Wikipedia compared to other Web sites among results on Internet search engines

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
1	Law (2011) [126]	Observational analytic design	Wiki (Wikipedia)
1	Lemley (2009) [113]	Survey	Wiki
1	Limdi (2011) [128]	Survey	Wiki (Wikipedia)
1	Martin (2011) (G) [127]	Survey	Wiki (Wikipedia)
1, 3	Sandars (2007; a) [114]	Survey	Wiki
1, 3	Sandars (2007; b) [189]	Survey	Wiki
1	Sandars (2008) [115]	Survey	Wiki (Wikipedia)
1	Santos (2007) [129]	Survey	Wiki (Wikipedia)
1,2	Schweitzer (2008) [121]	Survey	Wiki (Wikipedia)
1	Usher (2011) [118]	Survey	Wiki
1, 3	Williams (2011) [110]	Survey	Wiki
2	Aldairy (2011) [133]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Ayes (2010) (A) [190]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Clauson (2008) [61]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Czarnecka-Kujawa (2008) (A, G) [134]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)

Software used	Context of study	Speciality	Type of outcomes reported
MediaWiki	To investigate the sources of online information about prescription drugs used by consumers	Pharmacy / toxicology	Number of times a Web site appeared as the first result in search engines; Wikipedia page hits for prescription drugs in 2008 and 2009
N/A	To investigate which social networking tools are being used in the curricula of medical and nursing schools	Medical and nursing education	Prevalence of use
MediaWiki	Prospective study of patients attending Inflammatory bowel disease clinics	Gastroenterology	Ranking of popularity of different web sites and their trustworthiness
MediaWiki	To assess the information literacy skills of first year pharmacy students	Pharmacy, education	Search strategies used by students
N/A	Survey of medical students and qualified medical practitioners	Medical Education	Survey to determine familiarity with different social media; barriers to their use
N/A	Survey of students skills, experience and views on information technology	Medical Education	Previous use of wiki, attitudes towards wikis
MediaWiki, PBworks	To identify the extent of use of social media by medical students	Medical Education	Prevalence of use
MediaWiki	To evaluate the use of Internet by patients from a urology clinic	Urology	Ranking of the most visited web pages
MediaWiki	To examine Wikipedia's coverage of psychology-related concepts, its accessibility, and to describe how undergraduate students use Wikipedia	Mental health	Coverage; use of Wikipedia for personal use, school-related work, and as a formal reference in academic work
Twine: www.twine.com (now bought by www.evri.com)	Types of social media used by allied health professions in Australia	Health care in general	Prevalence of use
Wikispaces	Student use of wikis to support problem-based learning	Emergency medical services, education	Student attitudes on group work using wikis
MediaWiki	Dentofacial deformities	Oral and maxillofacial surgery / orthodontics	Quality and reliability of UK websites providing information on orthognathic and jaw surgery to patients
MediaWiki	Overdoses and poisoning / toxicologic emergencies	Toxicology	Comparison of Wikipedia toxicology content with content from Poisindex
MediaWiki	Quality of drug information in Wikipedia	Pharmacy	Scope, completeness, and accuracy of drug information in Wikipedia compared to that of a Medscape Drug Reference
MediaWiki	Study on the comprehensiveness, reliability and readability of Wikipedia concerning ICD-9 and ICD-10 gastroenterology diagnostic codes	Gastroenterology	Comprehensiveness, reliability and readability

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
2	Devgan (2007) (A, G) [58]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Dobrogowska-Schlebusch (2009) [99]	Descriptive quality assessment of wiki content paper	Wiki (see footnote for the list of names of wikis evaluated **********)
2	Friedlin (2010) [132]	Descriptive quality assessment of wiki content	Wiki (Wikipedia)
2	Haigh (2011) [136]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Hanson (2011) [104]	Descriptive quality assessment of wiki content paper	Wiki (Dermpedia: www.dermpedia.org [191]; Medpedia: http://web.archive.org/web/ 20130115090302/http://www.medpedia.com/about [37] and Wikipedia)
2	Johnson (2008) [131]	Survey	Wiki (Wikipedia)
2,3	Kim (2010) [54]	Descriptive quality assessment of wiki content paper	Wiki (Pathology informatics curriculum wiki: http://pathinformatics.wikispaces.com) [75]
2	Lavsa (2011) [135]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Leithner (2010) [195]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Lorenz (2010) [183]	Descriptive quality assessment of wiki content paper	Wiki (German-language Wikipedia)
2	McInnes (2011) [182]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)

Software used	Context of study	Speciality	Type of outcomes reported
MediaWiki	Internal validity of Wikipedia as a medical and surgical reference	Surgery	Quantitative metrics of quality (number of edits, unique editors, and references) and evidence of qualitative rigour (accuracy, completeness, discussion of indications and risks, and suitability for patients).
See footnote to see the names of software used for each wiki**********	Assessment of the quality of 52 medical wikis using Health Summit Working Group Quality Criteria and experiences with another wiki created for migrant health issues in Europe (http://mighealth.net/eu/)	Public health	Credibility (source, currency, relevance/utility, editorial review process for the information); Content (accuracy, completeness, disclaimer); Disclosure (purpose of the site, private policy); Links (selection, architecture, content, back linking); Design (accessibility, navigability, internal search capability); Interactivity; Caveats (clarification of whether site function is to market products and services or is it a primary information content provider)
MediaWiki	Logical observation identifiers names and codes (LOINC) database covered in Wikipedia	Medical taxonomy	Number of articles in Wikipedia that are exact matches, partial matches or mismatches with parts of the LOINC database
MediaWiki	Assessing the quality of Wikipedia article references and sources used by nursing students	Nursing, education	Mean number of reputable sources per Wikipedia entry
(Dermpedia: http://drupal.org; [193] Medpedia: MediaWiki; Wikipedia: MediaWiki)	Sampling of the top dermatology Internet resources, as assessed by a group of medical students	Dermatology	Websites ranked by using a matrix derived from the Silberg Criteria
MediaWiki	Rare medical entities which physicians in training would not be expected to know	Primary care and internal medicine	Frequency of searching different databases; efficiency of different search engines (number of links to find answer); correctness of answer
Wikispaces	Need for informatics training as part of pathology training	Pathology, medical informatics, education	Quality of Wikipedia pages linked to the Association for Pathology Informatics curriculum
MediaWiki	Assess the accuracy, completeness, and referencing of medication information in Wikipedia	Pharmacy	Accuracy, completeness, and referencing (fully, partially, or none)
MediaWiki	Scope, completeness, and accuracy of information found on osteosarcoma in Wikipedia	Oncology	Scope, completeness, and accuracy of information
MediaWiki	To assess the quality of articles on dentistry in Wikipedia	Dentistry	Number of scientific quality of articles
MediaWiki	Readability of websites on various causes of disease	General health information	Gunning FOG, SMOG, Flesch-Kincaid and Flesch Reading Ease tests

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
2	Mercer (2007) [196]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Mühlhauser (2008) [197]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Pender (2009) [63]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Rajagopalan (2010) [198]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Tulbert (2011) [199]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Wood (2010) [137]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia)
2	Wu (2010) (G) [96]	Descriptive quality assessment of wiki content paper	Wiki (Wikipedia) and Google knol
3	Andrus (2010) (A) [151]	Case study	Wiki
3	Archambault (2011) (G, A) [155]	Survey	Wiki
3	Belt (2011) (G, A) [105]	Case study	Wiki (IUI-Wiki (www.mijnzorgnet.nl/iui/w/wiki) and IVF-Wiki*******)
3	Blakely (2007) (G) [177]	Case study	Wiki (Wikipedia)
3	Bookstaver (2011) [138]	Quasi-experimental (before and after trial)	Wiki

Software used	Context of study	Speciality	Type of outcomes reported
MediaWiki	Review the handling of mental health topics in Wikipedia	Mental health	Shortcomings of Wikipedia articles on autism and other mental illness
MediaWiki	Using evidence-based medicine criteria, Wikipedia was compared to two major German health insurances for content and presentation of patient information	General health information	Quality of information based on a checklist containing 11 evidence-based criteria groups
MediaWiki	Compare the quality of entries on multiple sclerosis, otitis, conjunctivitis in Wikipedia and three traditional non-wiki databases (UpToDate, eMedicine, AccessMedicine)	Medical Education	Accuracy, coverage, concision, currency, suitability, accessibility and useability of the resources
MediaWiki	Compare the coverage, accuracy, and readability of cancer information from Wikipedia with a peer-reviewed web site (National Cancer Institute's Physician Data Query (PDQ) comprehensive cancer database	Oncology	Coverage, accuracy, and readability (Flesch-Kincaid grade level)
MediaWiki	Online patient education materials were comparatively assessed for readability and length in words	Dermatology	Flesch-Kincaid Grade Level and Flesch Reading Ease Scale
MediaWiki	Evaluate the medical content of Wikipedia entries about respiratory diseases and assess whether it could contribute to Pathology teaching	Pathology, education	Accuracy, presence of obvious mistakes, and usefulness for pathology teaching
MediaWiki, Google Knol	Comparison of two kinds of online encyclopaedias Wikipedia (consumer-oriented) and Google Knol (expert-oriented)	General consumer health	Page views per year, text words, readability, page strength, citation numbers, and citation types
wikiacc.org	Nursing education	Nursing, education	Improved quality of work, satisfaction
N/A	Trauma care	Emergency medicine	Barriers and facilitators about the use of wiki-based reminders
MijnZorgNet BV (www.mijnzorgnet.nl) [258] (social media platform)	Infertility	Gynaecology	Feasibility of using a wiki as a patient participation tool
MediaWiki	Mental health	Consumer health	Report about a pharmaceutical company modifying content in Wikipedia
N/A	Evidence-based medicine teaching	Pharmacy, education	Pre/post-test measurement of the retention of 12 key concepts related to understanding and applying Evidence-based medicine principles; post-test opinion

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
3	Buzzi (2009) [200]	Case study	Wiki (Wikipedia)
3	Chiarella (2009) [171]	Case study	Wiki (Dealing with Autism http://4griffin.wetpaint.com) [257]
3	Ciesielka (2008) [145]	Case study	Wiki (614comm: Meadville Collaborative Community Project: http://614comm.pbworks.com) [259]
3	Cinnamon (2010) (G) [146]	Case study	Google docs
3	Cobus (2009) [139]	Case study	Wiki
3	Collier (2010) [72]	Case study	Wiki
3	Cousineau (2009) (G, A) [201]	Case study	Wiki (Wikipedia-trica)
3	Culley (2012) (G) [156]	Case study	Wiki
3	Damani (2009) (G, A) [202]	Case study	Wiki
3	Dhillon (2011) (A) [161]	Case study	Wiki
3	Felsen (2010) (A) [175]	Case study	Wiki
3	Gerber (2010) (A) [176]	Case study	Wiki
3	Hamilton (2008) (G, A) [140]	Case study	Wiki
3	Hamm (2009) (A) [147]	Case study	Wiki
3	Hawkins (2010) [160]	Case study	Wiki
3	Hulbert-Williams (2010) [141]	Case study	Wiki
3	Ioannis (2011) (A) [107]	Experimental (clinical trial)**	Google Docs
3	Jalali (2009) (A) [178]	Case study	Wiki (Medswiki: www.medswiki.ca)

Software used	Context of study	Speciality	Type of outcomes reported
JAWS screen reader, Accessible Rich Internet Applications	Making Wikipedia usable for the blind	Occupational health	Difficulties interacting with the interface
Wetpaint	Autism	Mental health	Barriers/facilitators encountered during the creation of a wiki
PBwiki/PBworks**	Nursing education	Nursing, education	Description of users experience with a wiki
Google Docs	International health	Public health	Utility and feasibility of using free and easy-to-use social media (including Google Docs) tools for injury surveillance in low-resource settings
Blackboard	Public health teaching	Public health, education	Description of a wiki used by public health students intended for students and professionals as opposed to health consumers
N/A	Nursing education	Nursing education	Comments from students about the use of a wiki
N/A	Paediatric department morning report supported by a wiki	Health care library science, paediatrics, residency education	Comments about impact of a wiki on attendance at morning report
Blackboard	Graduate nursing education	Nursing Education	Student comments about using a wiki
PBworks (premium wiki), Microsoft SharePoint	Health care librarians sharing search results for evidence in response to clinical questions	Health care library science	Comments about usability of PBworks premium wiki compared to Microsoft SharePoint
Google Sites	Musculoskeletal curriculum	Radiology, residency education	Radiology residents' overall impression about a wiki
PBworks	Disseminating educational materials and coordinating the educational program	Primary care and internal medicine, residency education	Written evaluations by the residents
MediaWiki	A web-based database for standard operating procedures in cardiac anesthesia	Anesthesia	Wiki usage statistics, evolution of a wiki
N/A	Evidence-based practice physical therapy course	Physiotherapy education	Comments from a student about the use of a wiki
N/A	Development of lead poisoning prevention tools	Toxicology	Comments from the participants about the use of a wiki
Blackboard	Global health issues	Nursing, education	Comments from students about the use of the course wiki
Wolverhampton Online Learning Framework (WOLF) platform	Applied psychology class	Mental health, education	Wiki contributions; post-test questionnaire
Google Docs	Prevention of cardiovascular disease with a shared online diary	Cardiology	Blood pressure levels, cholesterol levels, smoking status, minutes of physical activity
Wikispaces	Medical students using a wiki to share course content	Medical education	Wiki usage statistics and barriers to contributions

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
3	Jones (2010) [154]	Case study	Wiki
3	Kardong-Edgren (2009) [148]	Case study	Wiki (CPR Training Doses Research Site: http://cprstudy.wetpaint.com)
3	Kitson-Reynolds (2009) [149]	Case study	Wiki
3	Koerner (2011) (G, A) [152]	Quasi-experimental (before and after trial)	Wiki
3	Kraft (2009) (G, A) [203]	Case study	Wiki
3	Krebs (2009) (A) [181]	Survey	Wiki (Neuroanatomy at UBC: www.neuroanatomy.ca) [204]
3	Lanning (2010) [158]	Case study	Wiki (Palliative Care Resources for Physician Assistants: http://palliativecareforpas. wetpaint.com) [205]
3	Lauber (2009) [180]	Case study	Wiki (ATEP Wiki)*****
3	Llambí (2011) [142]	Quasi-experimental (before-and after trial)	Wiki
3	Ma (2008) [102]	Case study	Hybrid wiki (OrthoChina: www.orthochina.com) [206]
3	Matlin (2009) (G, A) [207]	Case study	Wiki
3	Meenan (2009) [166]	Case study	Wiki (RadIT)*******
3	Miller (2009) [159]	Case study	Wiki
3	Mirk (2010) [162]	Quasi-experimental (before and after trial)	Wiki

Software used	Context of study	Speciality	Type of outcomes reported
LearnJCU (James Cook University virtual learning environment)	Learning environment where on-campus and distance students were able to work together to produce material with a wiki	Social work, education	Student comments regarding the process and outcomes of a wiki assignment (issues and benefits)
Wetpaint	Uses of a wiki in nursing research to manage the content of a research team studying the effect of brief teaching on CPR skills	Nursing	Experiences with the use of a wiki
N/A	Process of enquiry-based learning in midwifery	Midwifery education	Evaluation of a wiki as a course compliment
N/A	Use of wiki to support a paediatric elective	Paediatrics, medical education	Pre and post satisfaction survey was administered to assess perceptions of a wiki and its ability to enhance learning
N/A	Providing employees of a large regional health system access to library resources on and off campus	Health care library science	Comments from clinicians involved in a pilot test and wiki usage statistics from Google Analytics
WebCT learning management system at University of British-Columbia	Wiki created as a reference database for students	Medical education	Students evaluations of the use and usefulness of a wiki
Wetpaint (www.wetpaint.com)	End-of-life/palliative education in physician assistant programs	Physician assistant, education	Student experiences with a wiki
PBworks	Athletic training education programs are exploring wikis to train Approved Clinical Instructors	Sports medicine and therapy, education	Instructor feedback after using a wiki
N/A	Continuing medical education of physicians to help patients stop smoking	Primary care and internal medicine, CME	Pre/post-test measurements of the skills of teaching tobacco cessation; percentage of physicians passing the tobacco cessation skills test
Custom-built application******	Continuing medical education about musculoskeletal disorders	Orthopaedics, CME	Wiki usage statistics and qualitative description of content
Wetpaint	Sharing of ressources to improve student researching skills	Pharmacy, education	Authors experience with wiki
MediaWiki	Internal knowledge management system sharing various informatics support tools within a radiology department	Radiology	Wiki usage statistics
Google Sites	During an advanced pharmacy practice rotation in acute care setting, wikis were used to store questions and answers that arise during rounds	Pharmacy, education	Survey of student opinions about wiki use
Wetpaint	Pharmacy students enrolled in a course called "Landmark trials in primary care" to learn how to apply evidence in practice	Pharmacy, education	Pre/post evaluation of students' attitudes, level of perceived usefulness, degree of involvement with wiki collaboration, and level of satisfaction with wiki collaboration (5-point Likert scale)

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
3	Moeller (2010) [108]	Experimental (RCT)	Wiki
3	Moen (2009) [106]	Case study	Wiki (RareICT: http://goo.gl/07MHm) [208]
3	Montano (2010) [170]	Case study	Wiki (WIKINVESTIGACION: www.wikinvestigacion.org) [209]
3	Morley (2011) [153]	Case study	Wiki
3	Morose (2007)(D) [167]	Descriptive quality assessment of wiki content paper	Wiki (Participatory ergonomics: 2 www.cre-msd. uwaterloo.ca/participatoryergonomics)********
3	Moser (2011) (G, A) [165]	Case study	Wiki
3	Mosquera (2010) (G) [179]	Case study	Google docs
3	Muir (2010) (A) [168]	Case study	Wiki (*UCLA Radiology Residents*: http://pediatricimaging.wikispaces.com) [211]
3	Musil (2011) (G, A) [150]	Case study	Wiki
3	Phadtare (2009) [27]	Experimental (RCT)	Google Docs
3	Philip (2008) [143]	Observational analytic design	Wiki

Software used	Context of study	Speciality	Type of outcomes reported
N/A	Comparison of three interactive components (wiki, chat and interactive diagnostic context) on learning, aspects in the context of a problem-based learning	Medical Education	Self-administered questionnaires: learning effect, communication; collaboration; student satisfaction; diagnostic approach; realism;
MinJournal.no is a social media platform developed by the University of Oslo and several major hospitals in Norway [208]	Create a collaborative environment for peer support and knowledge construction related to a rare anorectal anomaly	General health information	Experiences and feedback from participants
Wikispaces	A community of researchers developed a wiki for the sharing and development learning and investigation resources in a hospital setting	Health care library science	Needs of the research community; opportunities provided by Web 2.0 tools; definition of the spaces that would be developed: elements, members and different access levels
University of Bournemouth's virtual learning environment (myBU); Blackboard	Wikis were introduced in a virtual learning environment to support on ongoing sociology of health course	Nursing, Education	Students' online contributions; students' and teachers' comments
Wiki was developed on Centre of Research Expertise for the Prevention of Musculoskeletal Disorders website: www.cre-msd.uwaterloo.ca [210]	Developing a participatory ergonomics website to summarize and share important information	Ergonomics/ workers safety	Wiki usage statistics; exit questionnaire to explore: the dissemination of information using a wiki; the decision-making process based on the quality of information in a wiki; and reasons for contributing to a wiki
N/A	Wiki used to get feedback from stakeholders about measures to assess determinants of health	Primary care	Lessons learned from a natural experiment
Google docs	Veterans' health	General health care	Report about a HIPAA security breach because physicians and medical students used Google Docs to enter notes about patient care
Wikispaces	Wiki used by residents to share interesting cases	Radiology, residency education	Comments about experience using a wiki
N/A	A wiki was used as a virtual learning environment	Pharmacy and social sciences, education	Students' comments about the use of a wiki
Google Docs	Google docs was used to teach scientific writing skills	Health care Education	Manuscript quality (Six-Subgroup Quality Scale); satisfaction; post hoc number of communication events (emails or phone calls) between participants and mentors
MediaWiki	Reverse teaching methodology in which students are given disease diagnosis and then asked to construct a patient case on a wiki to learn about clinical anatomy	Medical Education	Student confidence (7-point Likert scale) about different clinical skills; absolute increase in percentage of students feeling confident (more than 4 on Likert scale)

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
3	Powers (2009) (G, A) [212]	Case study	Wiki
3	Seebregts (2009) [76]	Case study	Wiki (OpenMRS Wiki: https://wiki.openmrs.org) [213]
3	Shaw (2010) [144]	Case study	Wiki (Marshall-Smith Wiki: www.marshallsmith.org) [214] *******
3	Steininger (2010) [174]	Survey	Wiki
3	Streeter (2007) [169]	Case study	Wiki (RadiologyWiki: www.RadiologyWiki.org) [262]
3	Stutsky (2009) (D) [109]	Experimental (RCT)	Wiki
3	Umland (2011) (G) [157]	Case study	Wiki
3	Van der Schoor-Knijnenburg (2009) [103]	Case study	Wiki (FreyaWIKI: www.freyawiki.nl) [216]
3	Varga-Atkins (2010) [32]	Case study	Wiki (PPD wiki)*****
3	Wan (2009) (D) [101]	Case study	Hybrid wiki (Wikibreathe tool/OCTAPUS: http://knowledgetranslation.ca/octapus/login.php)
3	Welsh (2007) [163]	Case study	Wiki (DrugScope Procedure Wiki)*****
3	Wright (2009) [172]	Case study	Wiki (Clinfowiki: www.clinfowiki.org) [217]

Software used	Context of study	Speciality	Type of outcomes reported
PBwiki	Wiki used to enable students to identify and gain access to relevant educational resources	Osteopathy, Health care library science, education	Comments about using a wiki
MediaWIki; since 2010, OpenMRS Wiki is powered by Open Source Atlassian Confluence team collaboration software (www.atlassian.com)	OpenMRS Implementers have created a wiki to share resources about implementing OpenMRS (an open source electronic medical record mainly used for HIV patients in Africa)	Public health	Discussion about the benefits of using a wiki
N/A	Description of a wiki to facilitate data collection and sharing about the phenotype and natural history of the rare Marshall-Smith Syndrome	Medical genetics	Discussion about the benefits of using wiki
N/A	Web 2.0 portal supervised by medical experts to disseminate credible information to consumers	Primary care and internal medicine	Assessment of patients' and physicians' needs; willingness to participate in development
MediaWiki	Creation of a dynamic online radiology educational resource	Radiology, education	Discussion about challenges and benefits of creating RadiologyWiki
PBwiki (http://pbwiki.com) [215] *********	N/A	Nursing	Empowerment: CWEQ-II (Conditions of Work Effectiveness Questionnaire-II); Psychological Empowerment Instrument; Measuring Leadership Practices (The Leadership Practices Inventory (LPI))
N/A	Women's health course in pharmacy curriculum	Pharmacy, education	Student evaluations about the usefulness of a wiki
Custom-built application	Production of a multidisciplinary guideline for subfertility care involving patients	Gynecology	Perceived benefits expressed by author
University of Liverpool virtual learning environment with Teams LX wiki (Blackboard)	Problem-based learning course added to a wiki to teach professionalism	Medical Education	Student and facilitator views about wiki use
Custom-built application***	Reverse engineering of content as a task for finding usability problems using the Wikibreathe tool to develop an asthma action plan	Respirology	Systems usability scale (ten-item scale each using a 5-point Likert scale giving a global view of usability); user (patients, clinicians) attitudes towards the tool
N/A	Internal wiki used as content management system to share procedures, self-guided training and tacit knowledge	Pharmacy	Author's experience with using a wiki
MediaWiki	To provide clinical informaticians a place to share experiences and clinical decision support content	Medical informatics	Wiki usage statistics

Theme	Authors, Year of publication, Type of publication*	Study design	Type of CWA (name of CWA and URL if available)
3	Wu (2009) (G) [74]	Quasi-experimental (before and after trial)	Wiki
3	Yates (2011) [164]	Case study	Wiki (Intelink: www.intelink.gov [31]; and U.S. Air Force Chief of Staff's Crisis Action Team (AFCAT) SharePoint site*******)
3	Yu (2011) (A) [173]	Case study	Wiki (Beth Israel Deaconess Medical Center hospitalist wiki site*******)

Notes:

* G=Grey literature; A=Abstract; D= Dissertation.
** PBworks was formally known as PBwiki.
** Methods for this abstract are very poorly described. It is impossible to determine if the paper was randomized or not. All that is mentioned is that it was a clinical trial.
*** This application was developed with the following software: jQuery, version 1.3.1 (a JavaScript library with built-in AJAX functions was used for the client-side interaction); wkpdf, version 0.2 (used for PDF generation); PHP, version 5.2 (including PEAR and MDB2) (used for server-side functionality); and MySQL, version 5.1 (used for databases).
**** Both Wikipedia and WikiHealth are powered by MediaWiki.
***** URL was not found.
****** OrthoChina was built to guard against copyright infringement and maintain safety of the operating system, the author selected free open-source applications for the operation of OrthoChina: Redhat Linux AS2 (operating system; Redhat Inc., Beijing, China, www.redhat.com.cn) and MySQL (database; of MySQL AB, Cupertino, CA, http://www.mysql.com) in conjunction with Tomcat-connector, Apache and Tomcat (Apache Software Foundation, Forest Hill,MD, http://www.apache.org). The Web site is designed and structured using a modified wiki concept. 1) Web content is created collaboratively by users through an Internet browser. 2) Information may be posted, edited, deleted, and updated by anyone with permission to do so, at any time. 1) The moderator can post content in any page, but can only edit, delete, and update the content in the specific pages he moderates. 2) The other users can only post content in forums (pages open for discussion), and can only edit and update the content posted personally, but they cannot delete the content once posted. 3) All content is open to viewing, and is monitored by the general orthopaedic users. 4) All editing, deleting, updating, credit score increasing and decreasing steps are tracked in detail, such as time, IP address, user, etc.
******* No URL could be found. This wiki is closed and password protected.
******** URL is no longer active.
********* Platinum level PBwiki (now PBworks): allows for enterprise-grade encryption on all Web pages).

Software used	Context of study	Speciality	Type of outcomes reported
N/A	Wiki-supported course teaching technology and information skills for nursing students	Health care library and nursing, education	Pre/post information literacy levels and students' opinions
MediaWiki (Intelink) and Microsoft SharePoint (AFCAT site)	US agencies employed wikis as the main knowledge management system to organise disaster response in Haiti Earthquake	Disaster management	Perceived benefits and challenges related to using wiki
Microsoft SharePoint	A closed and secure wiki was used as a content management system to share information in a hospitalist group	Primary care and internal medicine	Wiki usage statistics and key elements for success

********** List of 52 wiki assessed in Dobrogowska-Schlebusch paper, URL and software used

Ask Dr Wiki [218]	http://askdrwiki.com/	MediaWiki
Clinfowiki [217]	http://www.clinfowiki.org/wiki/index.php/Main_Page	MediaWiki
Billingwiki	n/a	n/a
Consumer Health Information Service [219]	http://chis.wikidot.com/about	Wikidot (www.wikidot.com)
Demystifying Depression [220]	http://en.wikibooks.org/wiki/Demystifying_Depression	MediaWiki
Diabetes Wiki [221]	http://diabetes.wikia.com/wiki/Diabetes_Wiki	Wikia (MediaWiki)
Diagnostic Radiology [222]	http://en.wikibooks.org/wiki/Diagnostic_Radiology	MediaWiki
DocCheck Flexicon [223]	http://flexikon.doccheck.com/en/Special:Mainpage	n/a
EBM Librarian [224]	https://sites.google.com/site/ebmlibrarian/home	Google Sites (previously on Wetpaint)
Emergency Medicine [225]	http://en.wikibooks.org/wiki/Emergency_Medicine	MediaWiki
Flu Wiki [226]	http://www.fluwikie.com/&refdoi=10.1186/1472-6920-6-41 (http://www.newfluwiki2.com)	SoapBlox
Ganfyd [30]	http://www.ganfyd.org	MediaWiki
Handbook of genetic counselling [227]	http://en.wikibooks.org/wiki/Handbook_of_Genetic_Counseling	MediaWiki
HealthGrid Wiki [228]	http://wiki.healthgrid.org/Main_Page	MediaWiki
Immunology [229]	http://en.wikibooks.org/wiki/Immunology	MediaWiki
Wikikidney [230]	http://www.wikikidney.org/index.php?title=Main_Page	MediaWiki
Medical Imaging [231]	http://medicalimaging.wikia.com/wiki/Main_Page	Wikia (MediaWiki)
Mla-hls [232]	http://mla-hls.wikispaces.com	Wikispaces
Mighealth (Migrant health) [233]	http://www.mighealth.net/uk/index.php/Main_Page	MediaWiki
ECGpedia [234]	http://en.ecgpedia.org/wiki/Main_Page	MediaWiki
The McGill Global Health Resource Guide [235]	http://wikisites.mcgill.ca/GlobalHealthGuide/index.php/Main_Page	MediaWiki
EBHC [236]	http://ebhcstrategies.wetpaint.com	Wetpaint
CHI TPL	n/a	n/a
Neurodegeneration Research Wiki [237]	http://wiki.iop.kcl.ac.uk/default.aspx/Neurodegeneration/Neurodegeneration%20Research%20Wiki.html	n/a
Pharm Lib [236]	http://pharmlib.pbworks.com/w/page/16284404/FrontPage	PBworks
PubDrug	n/a	
Quality of Medical Data [239]	http://medicaldata.wikia.com/wiki/Main_Page	MediaWiki (wikia)
Radiation Oncology [240]	http://en.wikibooks.org/wiki/Radiation_Oncology	MediaWiki
RadiologyWiki [262]	http://www.radiologywiki.org/wiki	MediaWiki
Radiopaedia [241]	http://radiopaedia.org	TrikeApps

		(http://trikeapps.com/projects/powerful/radiopaedia) (Radiopaedia was previously on MediaWiki)
RadsWiki	n/a	n/a
Rosacea Wikibook [242]	http://en.wikibooks.org/wiki/Rosacea	MediaWiki
Wikiversity School:Medicine [243]	http://en.wikiversity.org/wiki/School:Medicine	MediaWiki
Street Medic Wikia [244]	http://medic.wikia.com/wiki/Main_Page	MediaWiki (wikia)
Surgery [245]	http://en.wikibooks.org/wiki/Surgery	MediaWiki
UBC HealthLib Wiki (HLWIKI) [246]	http://hlwiki.slais.ubc.ca/index.php/UBC_HealthLib-Wiki_-_A_Knowledge-Base_for_Health_Librarians	MediaWiki
WebHealth [247]	http://webhealth.com/about/	WordPress (http://wordpress.com/)
Wellness Wiki [248]	http://wellness.wikispaces.com	Wikispaces
WikiCancer [249]	http://www.wikicancer.org	Wetpaint
WikiEcho [97]	http://www.wikiecho.org/wiki/Main_Page	MediaWiki and Semantic MediaWiki (http://www.semantic-mediawiki.org/wiki/Semantic_MediaWiki)
WikiHealth [260]	http://www.wikihealth.com/Main_Page	MediaWiki
WikiHealthCare [250]	http://wikihealthcare.jointcommission.org/bin/view/Home/WebHome	TWiki
WikiMD	http://www.wikimd.org/index.php/Main_Page (broken link)	MediaWiki
Wikisurgery	http://www.wikisurgery.com (broken link)	MediaWiki
WiserWiki [251]	http://www.elsevier.com/about/press-releases/health-sciences/elseviers-wiserwiki-allows-physicians-to-update-evidence-based-medical-information-with-experience-based-practice-insights	n/a
Nursing Wiki (Pflegewiki) [252]	http://www.pflegewiki.de/wiki/Hauptseite	MediaWiki
OpenWetWare [38]	http://openwetware.org/wiki/Main_Page	MediaWiki
OncoWiki [256]	http://oncowiki.info/index.php?title=Main_Page	MediaWiki
Orthopaedic Surgery [253]	http://en.wikibooks.org/wiki/Orthopaedic_Surgery	MediaWiki
Human Physiology [254]	http://en.wikibooks.org/wiki/Human_Physiology	MediaWiki
MUSC	n/a	
Pharmacology [255]	http://en.wikibooks.org/wiki/Pharmacology	MediaWiki
Wiki Doc [98]	http://www.wikidoc.org/index.php/Main_Page	MediaWiki and Semantic MediaWiki (http://www.semantic-mediawiki.org/wiki/Semantic_MediaWiki)

Appendix 2. Characteristics and findings of included studies

Author (year of publication) Country	Characteristics of population studied	Response rate (%) (Respondents (n)/ size (n) of total population)	Results
CWA use in specific projects			
Gupta (2010) [263] Canada	18 Health care professionals (Respirologists, Primary care physicians and Asthma Educators) and 21 patients	90% (35/39)	The proportion of use is not presented; Participants logged in 4.4, 5.8, 6.4, and 7.1 mean times/week; for 14, 16, 37, and 25 mean minutes/day; making 6.3, 6.0, 7.2, and 9.3 mean changes/day; 77% (27/35) found the tool effective
Kohli (2011) [53] USA	Radiology residents in a single radiology residency program	85% (51/60)	Wiki visits (mean): 5.6 times a week; Know how to edit wiki: 78% (n=40); Know how to add new page: 37% (n=19); Plan to add content to a wiki in the future: 71% (n=36)
Williams (2011) [110] Australia	Undergraduate paramedic students (2nd year); Male/Female: 9/20; Age: 21 respondents were 25 years old or less	49% (29/59)	Recommend using wiki in future courses: 41% (n=12); 41% (n=12) were neutral for this aspect; 14% (n=4) did not recommend its future use
CWA use in general (including Wikipedia)			
Alkhateeb (2011) [119] USA	Pharmacists in West Virginia attending a conference	100% (50/50) (note: all pharmacists attending a conference)	The vast majority of respondents reported using at least one type of social media tool, with the most frequently used applications including: YouTube (74%), Wikipedia (72%) and Facebook (50%).
Archambault (2010) [29] (G) Canada	Fifth; year residents enrolled in a Royal College of Physicians and Surgeons of Canada training program in Emergency Medicine in Canada	71 residents had access to a Google Docs slideshow	102 landmark articles had been summarized and critically reviewed
Bender (2011) [130] (G) Canada	Scholars and the editors of the Open Medicine Wiki Asynchronous Telehealth Scoping Review: 12 editors registered with the wiki (5 team members and 7 other non; team members). There is only information on 4/7 of the non; team members (male: 3; Canadians: 3; age: 30 to 60 y; previous use of a wiki: 4; University; affiliated: 3; health researchers: 2; health administrator: 1; health practitioner: 1; previous contribution to a wiki: 1; conflict of interest: 1). Visitors came from 66 different countries, with 72.2% of visits originating from Canada or the United States	4/7 non; team members completed the registration questionnaire	1222 visits to the wiki, 3996 page views, 875 unique visitors, 5 visitors submitted a total of 6 contributions: 3 contributions were made to the article itself, and 3 to the discussion pages. None of the contributions enhanced the evidence base of the scoping review. User accounts: 61; "Genuine" user accounts: 13 "Fake" accounts: 21 created by either automated scripts or individuals entering malicious information that was either false or nonsensical.

Time of assessment of use	Contribution rate	Prevalence of use	Reason for CWA use
1 week period (year not specified)	N/A	N/A	A wiki; like tool was used to seek multiple; stakeholder input and agreement about the visual aspect of an Asthma Action Plan
3 year period (year not specified)	69% (n=35)	100% (n=51)	A wiki was used as a knowledge management system to support residents' work on a daily basis (schedules, phone numbers, dictation templates, rotation/ call information, educational content)
N/A	N/A	N/A	A wiki was used to support case; based learning in a course given to paramedic undergraduate students. The wiki supported the blended approach to case; based learning using a mix of face; to; face and e; learning asynchronous communication between the students. The course wiki seemed to be an ideal way to promote cooperative learning, the sharing of ideas and the joint of development of common artefacts.
2009 (October)	N/A	72%	This study describes social media use among pharmacists. Use was mainly for personal reasons.
2009	22% (16/71)	N/A	Google docs was used to update a summary of landmark articles in Emergency Medicine
2009 (June 9) to 2010 (April 10)	0.57% (n=5)	N/A	A scoping review was published on the Open Medicine Wiki to facilitate its updating by all readers

Author (year of publication) Country	Characteristics of population studied	Response rate (%) (Respondents (n)/ size (n) of total population)	Results
Brokowski (2009) [116] USA	Pharmacists from 78 different U.S. pharmacy associations contacted using a mailing list; mean age: 48 years (range 23–86 y); Male/Female ratio: 44%/66%; mean experience 23 years (range 0–65 y); Degree: B.Sc. (52%, n=549), PharmD (40%, n=422), Other (e.g., PhD, MSc.) (9%, n=95); Residency training (22%)	3% (1056/38110)	19% (69/369) respond that they trusted Wikipedia; 12% (43/369) would recommend Wikipedia to other pharmacists; 7% (25/369) would recommend Wikipedia to consumers/patients; 28% reported using it to obtain drug information; 28% of the respondents who reported using Wikipedia to obtain drug information were familiar with who edits and manages the Web site.
Dodson (2011) [111] USA	Librarians in health science or/and hospital	N/A (10 respondents)	The most common department that librarians reported supporting with blogs or wikis was the medicine department, followed by pediatrics and family medicine.
Gonzalez de Dios (2011) [120] Spain	Pediatric neurologists and residents attending a conference	100% (44/44) (36 pediatric neurologists, 8 residents)	91% of participants did not use wikis, 7% used them seldomly, and 2% used them often. 84% did not use Google Docs, 16% used it seldomly, 0% used it often.
Harris (2010) [112] USA	1st year psychology students	N/A (Note: no information on the general population.) (271 respondents)	First year students used information obtained from Wikipedia; 36% (n=97) used Wikipedia information for research papers, presentations, and other course requirements; 63% (n=171) never, rarely, or occasionally attempted to verify information obtained from Wikipedia by checking other sources.
Hickerson (2009) [122] (G) USA	Users of Wikipedia (n=45) and WikiHealth (n=16) were surveyed online about their use of these wikis compared to none; wiki sites. College training (>4y): 38% (n=25) Postgraduate degree: 41% (n=27). Income more than $75,000 (US)/year: 43% (n=28). Caucasian: 80% (n=52). Male: 68% (n=44). Hours spent on the Internet (>21h/week): 47% (n=31). Hours spent on the wiki (>5h/week): 49% (n=32)	Response rate unknown; 65 respondents	More participants were committed to using a wiki in the future compared to none; wiki sites. The overall dialogic scores for the two wikis were also found to have positive and significant correlations to finding the website valuable and users' commitment to future use. [a]

Time of assessment of use	Contribution rate	Prevalence of use	Reason for CWA use
2009 (February 2; March 14)	N/A	35% (369/1056)	Wikipedia was used to obtain medication indications and drug information
2009	N/A	N/A	Wikis were used to support patient care and educational activities of medical departments (medicine, pediatrics and family medicine).
2010 (October)	N/A	9% (wikis); 16% (Google Docs)	This paper surveyed the types of web and web2.0 resources used by clinicians
N/A	N/A	64% (n=173)	This paper explores how Wikipedia is used by 1st year psychology students. Students use it as a source of general information and for academic purposes.
2 month period (year unknown)	N/A	N/A	Both wikis (Wikipedia and Wikihealth) were used for general health information.

Author (year of publication) Country	Characteristics of population studied	Response rate (%) (Respondents (n)/ size (n) of total population)	Results
Hughes (2009) [42] UK	35 junior physicians were selected via stratified sampling of 300 graduates from a London medical school (to ensure adequate representation of top 10 specialties); mean age: 27 years; Male/Female ratio: 0.75:1; physicians were post; graduate year 2 or 3 (Foundation year 2 or Specialist training year 1)	63% (35/55)	Junior physicians used wikis in their medical practice; Junior physicians used Wikipedia to find medical information; Few junior physicians made regular contributions to a medical wiki site; main reason for using Web2.0 sites: ease of use: 93% (33/35); main barrier against using Web2.0: limits in quality of information found (trustworthiness): 72% (27/35)
Iyer (2011) [117] USA	43 health care professionals (35 physicians, 7 physician assistants, 6 residents, 1 nurse practitioner) and 36 pharmacists working in the community clinics of one university network; mean age (SD) for clinicians was 43.23 (9.52) years and for pharmacists was 40.19 (10.60) years; Female/Male ratio: clinicians: 60%/40%; pharmacists: 61%/39%; years of experience (SD): clinicians 11.76 (9.48) and pharmacists: 13.02 (10.09)	51% (79/154)	Health care professionals and pharmacists reported the use of Google or Wikipedia at least daily (note: impossible to differentiate). The top sources used at least daily for seeking drug information among: A) health care professionals: (1) drug information databases (46%; n=20) (e.g. Micromedex and ePocrates); (2) hand; held devices (23%; n=10); (3) other online sources [Google or Wikipedia] (19%; n=8); (4) medical literature indices [PubMed, Medline, and CINAHL] (14%, n=6). B) pharmacists: (1) drug information databases (78%; n=28) (e.g. Micro-medex and ePocrates); (2) other online sources [Google or Wikipedia] (28%; n=10); (3) medical literature indices [PubMed, Medline, and CINAHL] (19%, n=7); (4) hand; held devices (11%; n=4)
Judd (2010) [123] Australia	Undergraduate medical and biomedical students	No response rate[b]	Google was the most popular information seeking site: students' usage increased from 24% (n=1200) in 2005 to 31% (n=1550) in 2009; Wikipedia use increased between 2005 and 2009; Use of NIH sites (PubMed, MedlinePlus and the National Library of Medicine portals) declined from 8% (n=400) in 2005 to 4% (n=200) in 2009
Judd (2011) [124] Australia	Undergraduate medical and biomedical students; Computer session logs (n=620) of 1st; 2nd; and 3rd; year medical students' biomedical searches in an open; access computer laboratory	No response rate[c]	Website use for biomedical searches: 1 Google (69.8%, n=433); 2 Wikipedia (51.0%, n=316); 3 eMedicine (21.5%, n=133); 4 NIH (16.5%, n=102); 5; University's Library (13.4%, n=83). Students' Wikipedia use decreased depending on their training level ($p<0.001$)

Time of assessment of use	Contribution rate	Prevalence of use	Reason for CWA use
2008 (July)	3% (1/35)	80% (wikis) (28/35); 70% (Wikipedia) (25/35)	This paper identified the junior physician's reasons to use Web2.0 tools (including wikis): ease of use, quality of information (up; to; date compared to textbooks, broader scope, contained interactive images), to solve an immediate defined clinical problem and for background reading on a subject.
2009 (March 6th ; April 29th)	N/A	18% (n=8 health care professionals); 28% (n=10 pharmacists)	This paper attempts to determine where health care professionals obtain drug information for clinical care and to stay updated on the latest drugs
2005 ; 2009	N/A	2005: 2% (n=100); 2009: 16% (n=800)	Wikipedia was used to find biomedical information
2007 (April/May)	N/A	Overall: 51%; 1st year students: 70.2% (132/188); 2nd year students: 49.5% (98/198); 3rd year students: 36.8% (86/234)	Wikipedia was used to find biomedical information

Author (year of publication) Country	Characteristics of population studied	Response rate (%) (Respondents (n)/ size (n) of total population)	Results
Laurent (2009) [125] UK	N/A[d]	N/A	Wikipedia ranked among the first ten results in 71; 85% of search engines and keywords tested. Wikipedia surpassed MedlinePlus and NHS Direct Online (except for queries from the latter on Google UK). Wikipedia ranked highest for rare diseases. Wikipedia articles were viewed more often than MedlinePlus Topic pages (p=0.001) but for MedlinePlus Encyclopedia pages, the trend was not significant (p=0.07, Jan 2008) and (p=0.10, June 2008).
Law (2011) [126] USA	Consumers	No response rate[e]	For generic drugs, Wikipedia is the first result for: 84.9% (236/278) Google.ca searches; 84.2% (234/278) Bing searches; 86.3% (240/278) Yahoo searches; 21.6% (60/278) Google.com searches. The National Library of Medicine is the first result for 74.8% (208/278) Google.com searches. For brand name drugs, Wikipedia is the first result for: 1% (2/198) Bing searches; 1% (2/198) Google.ca searches; 1% (2/198) Yahoo searches; 0.5% (1/198) Google.com searches. The National Library of Medicine is the first result for 71.7% (142/198) Google.com searches. Drug.com is the first result for 54.5% (108/198) Bing/Google.ca/Yahoo/Google.com searches.
Lemley (2009) [113] USA	Medical school educators and Nursing school educators (using mailing lists from different organizations: DR; ED, American Association of Colleges of Nursing Instructional Leadership Network, Association of Academic Health Sciences Libraries)	3% (55/1679) (36 Medical school educators and 19 nursing school educators)	The most common Web 2.0 tools used in the curricula of medical schools (in order from most frequent to least frequent): 1 none, 2 podcasting, 3 videocasting, 4 wikis, 5 blogs, 6 Flickr, 7 YouTube, 8 MySpace/Facebook, 9 Moodle. In nursing schools the most frequent Web2.0 tools are (in order from most frequent to least frequent): 1 none, 2 podcasts, 3 videocasts, 4 wikis, 5 blog, 6 Moodle, 7 Flick.

Time of assessment of use	Contribution rate	Prevalence of use	Reason for CWA use
2008 (Aug 19; 23 and Sept 12; 13)	N/A	N/A	Wikipedia was used to find general health information
2010 (June)	N/A	N/A	Wikipedia used as a source of drug information.
N/A	N/A	N/A	Using Web2.0 tools for teaching

Author (year of publication) Country	Characteristics of population studied	Response rate (%) (Respondents (n)/ size (n) of total population)	Results
Limdi (2011) [128] UK	104 consecutive patients consulting an Inflammatory bowel disease clinic; age range: 45 to 64; Male/Female ratio: 46%/54%; highest educational level: high school/ comprehensive (46.2%, (n=48)), sixth form/technical college: (14.4%, n=15), university graduate (32.7%, n=34), postgraduate (4.8%, n=5)	100% (104/104)	The most popular site was Crohn's and Colitis UK (n=24) with 22 "useful" and 0 "poor quality" ratings. Wikipedia was second (n=21) with 13 "useful" and 5 "poor quality" ratings.
Martin (2011) [127] (G) USA	14 first; year pharmaceutical students	100% (14/14)	Typical search strategy was first using Wikipedia, then PubMed and then MD Consult
Sandars (2007; a) [114] UK	Medical students and psychology students	Response rate unknown; first year medical students (n=197) and psychology students (n=80)	Use of a blog or a wiki was not differentiated. Intention to use blogs/wikis in the future: yes: 5% (n=19); maybe: 42% (n=116) ; no: 26% (n=72). Rate of authoring a blog/wiki was not differentiated; Intention to author a blog/wiki in the future: yes: 5% (n=19); no: 37% (n=102); maybe: 35% (n=97)
Sandars (2007; b) [189] UK	Medical students and qualified medical practitioners members of British Medical Association Consultants (n=389), GP (n=96), Doctors in training (n=64), Medical students (n=593); Mean age of: (1) Consultant: 48.3, (2) GP: 42.3, (3) Doctors in training: 37.8, (4) Medical students: 24.4; Gender: Male: 49.6% (n=567), Female: 50.4% (n=575)	21% (1239/5889) (note: 6000 emails were sent but 111 did not work)	Familiarity with wikis: Consultant: 68.9% (n=268); GP: 59.4% (n=57); Doctors in training: 79.7% (n=51); Medical students: 72% (n=427)
Sandars (2008) [115] UK	All first; year medical students at Leeds University; Gender: Female: 67%, (n=142)/Male: 33% (n=70); age (mean): 19 y (range 17; 32, 90% < 21)	92% (195/212)	Previous contributions to a wiki: Male: 18% (11/65); Female: 2% (3/129); $p < 0.001$ (gender difference)
Santos (2007) [129] Spain	Urology patients. Age: 60.98 (SE 15.08) Gender: Male: 81.6% / Female: 18.4%	1062 respondents (note: 1111 questionnaires were received; 49 questionnaires were not usable)	Wikipedia was the fourth most visited website (among other Spanish; language sites).

Time of assessment of use	Contribution rate	Prevalence of use	Reason for CWA use
N/A	N/A	N/A	Wikipedia was used to find medical information about Inflammatory Bowel Disease
N/A	N/A	N/A	Wikipedia was used to find relevant biomedical and pharmaceutical information.
N/A	14% (n=38)	29% (n=80)	Using blogs or wikis for academic learning
2007 (July)	N/A	Consultants: 55.3% (n=215); GPs: 50.4% (n=58); Doctors in training: 57.8% (n=37); Students: 80.9% (n=480)	Using wikis for personal or educational use
2006 (October)	7.2%	N/A	Wikis used for e; learning
2006 (September to December)	N/A	N/A	Wikipedia used for health information about urology problems

Author (year of publication) Country	Characteristics of population studied	Response rate (%) (Respondents (n)/ size (n) of total population)	Results
Schweitzer (2008) [121] USA	This was a two part study among university psychology students: Part 1: First year psychology students; age (mean): 19.1 years; Female 54.7%/ Male 45.3%; Part 2: Senior psychology students (majors and 4th year students); age (mean): 23.5 years; Female 58.9%/ Male 41.1%;	Part 1: 38% (918/2400) Part 2: N/A (76 respondents; no information on the overall population)	Part 1: Familiarity with Wikipedia: 18.8% (n=173) had never heard of it; 17.6% (n=162) had heard of it 63,6% (n=584) had used it in the past 18.5% (n=170) reported using it on a regular basis. Frequency of: 1) personal use: regularly: 14.9% (n=137); once or twice: 41.7% (n=383); never: 43.4% (n=398); 2) use for high school paper: regularly: 16.9% (n=88); once or twice: 39.8% (n=365); never: 43.3% (n=397); 3) use for college paper: regularly: 4.1% (n=38); once or twice: 14% (n=129); never: 82% (n=753); 4) Wikipedia use as a reference in college paper: regularly: 2.4% (n=22); once or twice: 6.3% (n=58); never: 91.3% (n=838);5) reference to Wikipedia in psychology project: regularly: 0.6% (n=6); once or twice: 2.4% (n=22); never 97% (n=890). Part 2: Familiarity with Wikipedia: 14.5% (n=133) had never heard of it; 21.1% (n=194) had seen it but used rarely; 64.5% (n=592) were regular users; 28.9% (n=265) used it on a frequent basis. Reasons for Wikipedia use: 80.3% (n=737) out of curiosity; school related paper 77.3% (n=710); psychology specific paper: 43.1% (n= 396); never cited Wikipedia: 39.4% (n= 362); had edited Wikipedia: 6.1% (n=56)
Usher (2011) [118] Australia	935 Health care professionals; Psychiatrists: 1% (n=11), GPs: 11% (n=104), Social Workers: 12% (n=109), Dieticians: 14% (n=134),Chiropractors: 2% (n=15), Physiotherapists: 29% (n=271), Optometrists: 14% (n=128), Pharmacists: 17% (n=163); age: <30: 22.7% (n=212), 30; 50: 49.1% (n=459), >50: 28.2% (n=264); Clinical experience: <10 y: 33% (n=309); >10 y: 67% (n=626). Gender: Male: 38.5% (n=360)/Female: 61.5% (n=575). Practice type: Private practice: 64.7% (n=605); Government: 26% (n=244); Location: Major city: 57.4% (n=537); Inner regional 18.2% (n=170); Outer regional 18.8% (n=176); remote 5.6% (n=52)	Response rate unknown; 935 respondents answered online survey (note: 1,085 responses were collected; 150 responses excluded because of missing data)	Overall, 9.5% (n=89) of health care professionals stated that they used social media to deliver care to patients; 19.1% (n=179) stated that they would use social media for personal purposes only, and 71.3% (n=667) stated that they would not use social media at all. Ranking of different social media use for health care delivery based on the frequency of use in the last 12 months: 1 email; 2 Skype; 3 iPhone; 4 Facebook; 5 Twitter; 6 instant messaging; 7 mes-sage boards; 8 chat rooms; 9 blogs; 10 wikis 11 MySpace; 12 YouTube. Ranking of social media use for personal reasons based on the frequency of use in the last 12 months: 1 email; 2 Facebook; 3 iPhone; 4 Skype; 5 Twitter; 6 wikis; 7 instant messaging; 8 blogs; 9 YouTube; 10 message boards; 11 chat rooms; 12 MySpace; 13 Medworm; 14 Flickr

Time of assessment of use	Contribution rate	Prevalence of use	Reason for CWA use
N/A	6.1%	1st year students' personal regular use: 14.9% ; 18.5%; 1st year students' regular use for college paper: 4.1%; 1st year students' regular use of Wikipedia as a citation: 2.4%; 1st year students' regular use of Wikipedia as a citation for a psychology paper: 0.6%; Senior students regular use: 64.5%; Senior students' use of Wikipedia for a school related paper: 77.3%; Senior student use for a psychology paper: 43.1%	This paper assesses the prior use of Wikipedia by psychology students. Among stated uses were for personal use, school related writing projects and as formal reference in academic work.
2009	N/A	N/A	Use of Web2.0 tools for Health care delivery and personal needs

G = Grey literature.

a. The dialogical score is a composite score based on a summary of the scores obtained for ten questions assessing the 5 principles of dialogic public relations. These five principles express different aspects of how organizations must engage in dialog with their targeted public. Each question measures the level of agreement (on a five; point Likert scale) with 5 statements related to the five principles of dialogical public relations: mutuality, propinquity, empathy, risk and commitment.
b. Study included logging data In August and September of each year between 2005 and 2009, the first 5000 computer session logs in a computer laboratory were analysed to determine what Internet resources were being used by students.
c. 620 computer sessions searching for biomedical information were analyzed).
d. The aim of this study was to determine how often the English Wikipedia appears among the top search engine results for health; related queries: A) different sets of keywords were searched to determine the ranking of Wikipedia in Google, Google UK, Yahoo, MSN: 1; 1726 keywords from MedlinePlus index; 2; 966 keywords from the NHS Direct Online index; 3; 1,173 keywords from the U.S. National Organization of Rare Diseases index; B) Wikipedia and MedlinePlus Page view statistics were compared for the 20 most visited MedlinePlus Topic and Encyclopedia pages.
e. 2 studies were performed: 1) Four search engines (Bing, Yahoo, Google.com, Google.ca) were searched to determine the most common website returned for a list of the most dispensed generic and brand name drugs in the USA (n=278); 2) the number of unique Wikipedia page hits was determined for all study drugs.

Appendix 3. Quality of information in collaborative writing projects

Author (Year of publication) G=Grey literature	Who the info is defined to	Purpose	Methods to assess quality
Aldairy (2011) [133]	Patients	To evaluate 25 orthognathic and jaw surgery information pages including Wikipedia	A validated instrument was used (DISCERN instrument)
Ayes (2010) [190]	Consumers, health care professionals	To evaluate Wikipedia content on toxicology information	A locally-developed grading scale was used
Clauson (2008) [61]	Consumers	To compare the scope, completeness, and accuracy of drug information in Wikipedia with that of a free, online, traditionally edited database (Medscape Drug Reference)	A questionnaire developed by the authors. Scope was measured by the presence or not of an answer (% of presence of answers) and by number of omission errors. Completeness was measured as the percentage of answers that were complete (% of complete answers). Accuracy was measured by the number of inaccurate answers.
Czarnecka-Kujawa (2008) [134] (G)	Consumers	To assess the comprehensiveness, reliability and readability of Wikipedia's gastroenterology articles	World Health Organization ICD-10 and ICD-9 diagnostic codes in gastroenterology were correlated to articles on Wikipedia on the same topic. Reliability was measured by the number of peer reviewed articles referenced per article. Readability was measured with the Flesch-Kincaid readability test and four other standardized tests.
Devgan (2007) [58]	Consumers	To examine the quality of Wikipedia articles about the 39 most commonly performed surgical procedures in the USA	Two reviewers reviewed Wikipedia articles using self-developed quantitative metrics of quality

Results	Conclusion (of the authors of the paper)	Date of quality assessment	Vote counting based on authors' conclusions*
Wikipedia achieved the highest score (64/80), and the majority of websites fell well below the maximum score	By directing patients to validated web-sites, clinicians can ensure patients find appropriate information; however, further development of websites relating to orthognathic surgery is required.	2010 (May)	2
Wikipedia did not provide significant information on toxicology and was not significantly updated or corrected.	Wikipedia is not a good source of information for toxicology as it contains limited information on toxicology and sometimes erroneous information.	2009 and 2010	3
Scope: Wikipedia (40.0%) vs MDR (82.5%; p < 0.001). Dosing questions: Wikipedia (0%) vs MDR (90.0%). Errors of omission: Wikipedia (48) vs MDR (14). Completeness: Wikipedia (76.0%) vs MDR (95.5%) in MDR (p < 0.001). Wikipedia improved over time, as current entries were superior to those 90 days prior (p = 0.024). Accuracy (inaccurate answers): Wikipedia (0) vs MDR (4).	Wikipedia provided factually accurate drug information, but it was incomplete, much more likely to contain errors of omission, and thus, of more limited scope than the information available in MDR.	2008 (March)	2
Comprehensiveness: Of the 203 ICD-10 gastroenterology diagnostic codes: 168 (82.8%) had Wikipedia entries. Of the 178 ICD-9 gastroenterology diagnostic codes, 148 (83.1%) had Wikipedia entries. Reliability: 58/103 (56.3%) articles in Wikipedia were substantiated with at least one peer-reviewed reference. The average number of references per article was 6.8. Readability: Median Flesch-Kincaid grade level: 13.7; Mean Flesch reading ease score: 32.1; Median automated readability index: 14.9	Wikipedia's content in gastroenterology is comprehensive. The reliability is moderate. The articles are readable with a grade level of slightly higher than high school	N/A	2
Wikipedia indexed 35 (89.7%) of the most commonly performed surgical procedures. Appropriate articles for patients: 30 (85.7%) Percentage of articles with accurate information: 100% (n=35). Percentage of articles without critical omissions: 62.9% (n=22). Wikipedia articles addressed procedure indications (97.1%, n=34), while 62.9% (n=22) discussed risks. There was a correlation between an entry's quality and how often it was edited.	Wikipedia is an accurate though often incomplete medical reference. Participation of medical and surgical professionals in authoring Wikipedia entries may improve their quality and keep patients more informed.	N/A	2

Author (Year of publication) G=Grey literature	Who the info is defined to	Purpose	Methods to assess quality
Dobrogowska-Schlebusch (2009) [99]	Physicians, consumers, patients, health care professionals, medical and health students, scientists, medical librarians	To study the quality of 52 medical wikis and the correlation between the quality of wikis and the presence of a quality assurance system, the number of users and the type of software	Criteria created by the Health Summit Working Group (HSWG). All results are pooled (% represents the percentage of the 52 wikis that respected the quality criteria; except for the "links" category that had 23 wikis that could be assessed). Wikis were considered: very good if more than 75% of the HSWG criteria were met and good if between 65 and 75% of HSWG were met.
Friedlin (2010) [132]	Consumers	To evaluate the degree of medical knowledge and accuracy of information contained in Wikipedia.	Compare the amount of identical matches to the LOINC (The logical observation identifiers names and codes) database and Wikipedia entries for a random sample of 100 matches.
Haigh (2011) [136]	Nursing students	To assess the quality of references of a random sample of Wikipedia articles.	Citation tracking for the selected Wikipedia articles (n=132) were assessed using the typology developed by the British Department of Health in evaluating evidence.
Hanson (2011) [104]	Dermatologists	To assess the quality of online dermatology resources	Six students assessed the quality using the Silbert criteria. Top-rated resources were defined as a having a Silbert score of 13/20 or higher.
Hickerson (2009) [122] (G)	Consumers	To determine the perceived value of Wikipedia and WikiHealth compared to 15 non-wiki sites (eg, eMedicine and WebMD)	An online survey was performed with users of Wikipedia (n=45) and WikiHealth (n=16) to determine the perceived value of these wikis compared to the value of 15 non-wiki sites they used (e.g., eMedicine and WebMD).
Johnson (2008) [131]	Students (Primary Care and Internal Medicine)	To compare the utility and efficiency of Google with other medical and nonmedical web-based resources for identifying specific medical information	Students (N=89) used Google and other web-based sources to find answers for a 10-question multiple choice exam. Efficiency was measured by the number of links to find an answer.

Results	Conclusion (of the authors of the paper)	Date of quality assessment	Vote counting based on authors' conclusions*
Website Design (availability: 98%; navigation: 87%; searchability: 100%) Interactivity: 85% Credibility (source: 48%; update: 92%; correspondence 96%; reviewing procedure: 25%) Content (reliability: 46%; presence of legal notice: 54%) About this site (purpose of page: 85%; privacy policy: 33%) Links (selection: 74%; structure: 83%; content: 83%; backlinks: 40%) Disclaimer (advertising policy: 27%). Among the surveyed Wiki, 18 (35%) had a very good quality, and 10 (19%) were good. Among the 13 of the surveyed wikis that met the "reviewing procedure" criteria, 11 were characterized by very good quality.	Wikis can be an appropriate tool to build a medical or health information source, but only 54% of the reviewed wikis were of good or very good quality as measured by the HSWG criteria. Higher quality scores could be associated with a "reviewing procedure" to control access to certain authors. Wikis peer reviewed and moderated by experts are of better quality than those generated and published by the community of all Internet users.	2008 (August) to 2009 (April)	2
Of the 1705 parts queried, 1314 matching articles were found in Wikipedia. Of these, 1299 (98.9%) were perfect matches that exactly described the LOINC part.	Wikipedia contains a large amount of scientific and medical data and could effectively be used as an initial knowledge base for specific medical informatics and research projects.	N/A	1
In total 1473 (56%) of the references cited on the Wikipedia articles reviewed could be argued to come from clearly identifiable reputable sources. This translates to a mean number of reputable sources of 29 per Wikipedia article.	Wikipedia citations should be treated with some caution, but Wikipedia does have a role to play as a source of health related evidence, and as a useful tool in the teaching of critical appraisal and literature searching. It's use by nursing students when researching information to contribute to assignments should not necessarily be discouraged.	N/A	2
Wikipedia ranked in the top quality dermatology resources (Silbert score not available).	Cutting-edge online dermatology resources (including Wikipedia) represent excellent sources for continuing education for students and clinicians alike. Resources such as these likely represent the future of medical education, as they allow for self-directed and supplementary education as well as remote access.	2011 (July)	1
Information from Wikipedia and WikiHealth was perceived just as valuable as non-wiki website information. The overall dialogic scores for the two wikis were also found to have positive and significant correlations to finding the website valuable.[a]	Although a positive correlation exists between the dialogical aspect of wiki pages and perceived value, there remain questions that need further research to understand why the perceived value of wikis is not higher than the perceived value of non-wiki pages.	2 months (year unknown)	2
Wikipedia showed good answers for 96% (44 of 46 questions). It ranked second in terms of efficiency to find an answer compared to 6 other resources.	No conclusion concerning Wikipedia	2007 (January)	N/A

Author (Year of publication) G=Grey literature	Who the info is defined to	Purpose	Methods to assess quality
Judd (2011) [124]	Medical students	To determine medical student's (2nd and 3rd year) perception of the usefulness and reliability of 5 different websites	Medical students (n=502) were asked to grade the usefulness and reliability (five-point Likert scale) of Google, Wikipedia, the University of Melbourne Library, eMedicine and The National Institutes of Health[b]
Kim (2010) [54]	Pathology residents	To evaluate Wikipedia content about pathology informatics	Items from students' recognized curriculum (vida supra) were compared to the students' curriculum and assessed quality by using five-point Likert scales. Five topics were assessed.
Lavsa (2011) [135]	Students (pharmacy)	To assess the accuracy and completeness and referencing of the Wikipedia pages for the 20 top prescribed medications in the USA.	Four pharmacists independently assessed the articles for specific categories of information typically found in medication package inserts. Wikipedia articles were compared to package inserts, Micromedex Drugdex Evaluations, Clinical Pharmacology, and Lexi-Comp. Each article was evaluated for the presence of each category, and for each category that was present, the information was designated as accurate (no discrepancies from FDA labeling), complete (contain all subcategories), and referenced (fully, partially, or none).
Leithner (2010) [195]	Consumers	To assess the scope, completeness, and accuracy of information found on osteosarcoma in Wikipedia compared to the patient version and the health professional version of the US National Cancer Institute (NCI) website.	Using a questionnaire comprised of 20 questions, two surgeons and a medical student assessed the scope, completeness, and accuracy of information on osteosarcoma from Wikipedia, the patient version and the health professional version of the National Cancer Institute's (NCI) website. The answers to the 20 questions were verified with authoritative resources and international guidelines.
Lorenz (2010) [183]	Consumers and dentists	To assess the scientific quality of 265 articles on dentistry (German Wikipedia)	Wikipedia content was subjectively compared to recognized scientific sources (textbook, scientific articles, guidelines) and classified as "acceptable", "partially acceptable" and "inacceptable" for a textbook.

Results	Conclusion (of the authors of the paper)	Date of quality assessment	Vote counting based on authors' conclusions*
Among the 5 websites, Wikipedia was graded 3rd in usefulness (3.99) (after Google (4.38) and eMedicine (4.18)). Wikipedia ranked last in terms of reliability (3.26).	Students' reliance on and familiarity with known tools such and Google and Wikipedia may be contributing to underlying information literacy problems, effectively creating a barrier to the development of new information-seeking skills.	2007 (May)	3
Up-to-date: 4.18; Quality: 4.08; Completeness: 4.05; Appropriate for advanced learners: 3.93; Appropriate for beginners 3.85.	Wikipedia is a comprehensive, high quality, current and appropriate for beginners and advanced learners.	2010 (March)	1
Information categories most frequently absent were drug interactions and medication use in breastfeeding. Information on contraindications and precautions, drug absorption, and adverse drug events was most frequently found to be inaccurate. Descriptions of off-label indications, contraindications and precautions, drug interactions, adverse drug events, and dosing were most frequently incomplete. Referencing was poor across all articles.	Variability in the content, accuracy, completeness, and referencing of drug information in Wikipedia was found. Students should not use Wikipedia sources for referencing and it should not be used for patient care because of the potential for patient harm resulting from incomplete or inaccurate information.	N/A	3
NCI professional version: 50/60 points; NCI Patient version: 40/60 points. Wikipedia: 33/60 points. There was only a statistically significant difference between the NCI professional version and Wikipedia p=0.039). All three reviewers preferred Wikipedia when asked for the ease of use to find patient-related information.	The quality of osteosarcoma-related information found in the English Wikipedia is good but inferior to the patient information provided by the NCI. Wikipedia should include links to more definitive sources, such as those maintained by the NCI and professional international organizations. Frequent checks should make sure such external links are to the highest quality and to the best-maintained aggregate sites on a given health care topic.	2009 (April)	2
74 articles (28,4%): "appropriate for a medical textbook"; 146 (55,9%) articles: "partially qualified"; 41 (16%) articles: "not qualified". 220/261 (84,3%) articles on dentistry were appropriate for patient information; 123/261 articles (47,1%) presented a complete presentation of the topic.The quality of an article decreased with having more edits and editors.	Individuals interested in dental topics should not exclusively rely on Wikipedia. Increasing peer-review by experts might improve quality.	2008 (January)	2

Author (Year of publication) G=Grey literature	Who the info is defined to	Purpose	Methods to assess quality
McInnes (2011) [182]	Consumers	To calculate the readability of websites on various diseases.	The names of 22 health conditions were entered into five search engines, and the readability of the first 10 results for each search were evaluated using Gunning FOG, SMOG, Flesch-Kincaid and Flesch Reading Ease tests.
Mercer (2007) [196]	Consumers	To review Wikipedia's handling of mental health topics	One reviewer subjectively reviewed three articles (autism, bipolar disorders, reactive attachment disorder) for obvious errors or omissions.
Mühlhauser (2008) [197]	Consumers	To compare the quality of health information provided by the German Wikipedia and 2 German health insurances websites.	22 students investigated 1 topic and were reviewed by one of the co-authors. A checklist (47 evidence based items) was used.
Pender (2009) [63]	Students (medicine)	To address the suitability of Wikipedia as a source for medical students	One expert compared de-identified copies of Wikipedia, eMedicine, AccessMedicine and UpToDate articles using a self-developed scale to rank accuracy, coverage, concision, currency and suitability of the resources. Accessibility and usability were assessed by medical librarians.
Rajagopalan (2010) [198]	Consumers	To assess the quality of online cancer information on Wikipedia and the website of the National Cancer Institute's physician Data Query (NCI PDQ)	Information of the sources was compared to textbook information. Reliability (inter-observer variability and test-retest reproducibility), readability (calculated from word and sentence length) and accuracy (locally developed scoring system) were assessed.
Schweitzer (2008) [121]	Psychology (undergraduate students)	To assess Wikipedia's coverage of psychology-related concepts	No quality assessment method (study only assessed breadth of coverage). One author selected 100 psychology topics to review.
Tulbert (2011) [199]	Consumers	To assess the readability and length in words of online patient education materials	Online patient information was compared to information produced by the American Academy of Dermatology using the Flesch-Kincaid Grade Level (FKGL) and Flesch Reading Ease (FRE) tests.

Results	Conclusion (of the authors of the paper)	Date of quality assessment	Vote counting based on authors' conclusions*
Wikipedia articles (Reading Grade (RG)=15.21, 95% CI=14.44-15.99) were significantly harder to read than other .org websites (p<.001). Wikipedia articles were even more difficult to read than .edu sites and had a FRE score of 31.22 (95% CI=27.96-34.48) (a score close to being considered 'very difficult')	Some of the most frequent search results (such as Wikipedia pages) were amongst the hardest to read. Health professionals, with the help of public and specialised libraries, need to create and direct patients towards high-quality, plain language health information in multiple languages.	2010 (January)	3
The included mental health pages had missing information and poor discussions.	A higher quality of information would be desirable in a source so easily accessible.	2006 (July)	3
Results for the 21 topics in Wikipedia (987 items): Correct/fulfilled: 18% (n=174); Wrong/Not fulfilled: 3% (n=32); Incomplete/Partially fulfilled: 137(14%); Missing: 59% (n=582); Not applicable: 6% (n=62)	Neither German Wikipedia nor 2 major German health insurances provide medical information that sufficiently fulfils internationally agreed criteria for evidence based patient or consumer information.	2007 (December)	3
The entries in Wikipedia, in comparison with the other resources, were easy to access, navigate and well presented. Although reasonably concise and current, the Wikipedia entries failed to cover key aspects of two of the topics, and contained some factual errors.	Wikipedia was found to be very accessible but was judged unsuitable for medical students to base their learning on.	N/A	3
No differences in the combined depth and accuracy of content between Wikipedia and NCI PDQ. Controversial aspects of cancer care were poorly discussed in both sources. Wikipedia was significantly less readable than NCI PDQ (Flesch-Kincaid Grade Level score: 9.6 (SD 1.5) vs. 14.1 (SD 0.5) (p < 0.0001)).	Wikipedia and NCI PDQ entries have a comparable depth and accuracy but Wikipedia was less readable.	2009 (August)	2
Among the 100 topics 81 were covered in Wikipedia.	The results demonstrated that Wikipedia's coverage of psychological topics was comprehensive and prominently displayed on the major search engines.	N/A	N/A
Wikipedia proved significantly harder to comprehend than all other sources. None of the Wikipedia articles was below the ninth grade level, and 11 of 15 Wikipedia articles exceeded 12.0 on the FKGL. No articles from Wikipedia exceeded a FRE score of 60.0.	No single source of commonly used internet patient-education material demonstrates optimal features with regard to readability, length, and presence of photographic illustrations. Wikipedia should use professional editors to increase readability of articles destined for patient education.	2009 (April)	2

Author (Year of publication) G=Grey literature	Who the info is defined to	Purpose	Methods to assess quality
Wood (2010) [137]	Pathology students	To compare the content of Wikipedia to that of the Kumar et al Pathological basis of disease (8th ed) textbook	One pathologist trainee reviewed the content of 16 Wikipedia articles relating to different pathologies and subjectively compared them to the Kumar textbook content
Wu (2010) [94] (G)	Consumers	To compare the readability and six specific text features of Wikipedia and Knol.	Wikipedia articles and Google Knol pages were compared in different fields of which: Alzheimer's disease, autism, Helicobacter pylori, influenza, lung cancer, multiple sclerosis, subarachnoid hemorrhage and tuberculosis. Six features were compared: page views per year, text words, readability, page strength, citation numbers, and citation types. Readability was assessed using: Gunning-Fog Score, Flesch Kincaid Reading Ease, Flesch Kincaid Grade Level, SMOG Index, Coleman Liau Index, and Automated Readability Index

* 1: Mostly a reliable source, high quality info; 2: Partially reliable: e.g. needs improvement or updates; 3: Not reliable, should not be used.

a. The dialogical score is a composite score based on a summary of the scores obtained for ten questions assessing the 5 principles of dialogic public relations. These five principles express different aspects of how organizations must engage in dialog with their targeted public. Each question measures the level of agreement (on a five-point Likert scale) with 5 statements related to the five principles of dialogical public relations: mutuality, propinquity, empathy, risk and commitment.
b. This was a survey and 92% response rate among 549 surveyed.

Results	Conclusion (of the authors of the paper)	Date of quality assessment	Vote counting based on authors' conclusions*
The entries were generally informative, accurate, comprehensive and useful resources for medical education. The entries are generally well referenced and provide external links to other good resources.	Wikipedia is an informative and accurate source for pathology education, particularly if used in combination with other learning materials. Caution must be advised with regards to the medical information presented.	2009 (December)	2
Number of text words: no significant difference (p=0.327); Page views per year: Wikipedia: 145264.1 Knol 10144.5; p=0.12; Page ranking in search engines: Wikipedia: 0.629 vs. Knol 0.243 p=0.012; Citation numbers (all citations included): Wikipedia: 141 vs Knol 17 p=0.12; Readability: Wikipedia 8.5 Knol 9.875 p=0.048 (dwikipedia is easier to read); Citation of journals: Wikipedia: 8.602 vs Knol: 12.372; p= 0.042. Folk-oriented Wikipedia has better popularity, influence, ranking ability, and amount of references. Expert-oriented Knol provides more difficult articles and cites more authority resources. To improve Wikipedia, it needs to control citation numbers and cite more authoritative resources to increase accuracy and credibility. For Knol, it needs to do search engine optimization. Wikipedia AND Knol need to increase its readability to fit much more general readers	The result can help online encyclopedia's improve their quality from different viewpoints. In addition, users could choose appropriate articles from different valuable resources based on our investigations. The researchers have to conduct further studies with consideration of these shortcomings.	N/A	N/A

Multimedia Appendix 4. Characteristics and results of experimental studies

Author (Year)	Study design	Type of CWA (software)	Participants and context of study (field of study)	Intervention
Ioannis (2011) [107]*	Clinical trial**	Google Docs (Google Docs)	Patients (n=80) undergoing a 6-month secondary prevention program after an acute coronary syndrome (Cardiology)	Using an online diary, participants (n=35) had to log on at least once a month to enter their blood pressure measurements and minutes of physical activity. They had access to a Google Doc where they could find instructions from a physician who analyzed their online diary.
Phadtare (2009) [27]	RCT***	Google Docs (Google Docs)	2nd and 3rd year medical, physiotherapy and nursing students (n=48) enrolled in a scientific writing course had to write a scientific paper in groups of two. (Medical education)	Pairs (n=12) of students used Google Docs to write, review, edit and share their manuscripts online with their mentors who gave them feedback
Stutsky (2009) [109]**** (D)	RCT	Wiki (Platinum version *Peanut Butter Wiki* (PBwiki))	Nurse educators (n=51) participated in a 12-week online learning community with a wiki where storytelling was shared to develop nursing leadership practices. (Nursing)	Participants (n=26)***** had access to a wiki within a moderated learning community. The facilitator organized the wiki pages, posted stories, and assisted nurse educators in analyzing their own leadership stories
Moeller (2010) [108]	RCT	Wiki (not available)	Medical students (n=237) participating in a problem-based learning (PBL) course were enrolled in a multiple arm study comparing students (n=99) in a classical PBL (cPBL) course to students (n=138) participating in a blended PBL (bPBL) course involving different elearning tools including a wiki, a chat and an interatice diagnostic context. (Medical education)	bPBL with wiki support

* This paper is an abstract. No full text could be identified.

** Methods for this abstract are very poorly described. It is impossible to determine if the paper was randomized or not.

*** RCT: randomized controlled trial.

**** This paper is a PhD. dissertation.

***** In the end, some participants dropped out of the project and left 19 participants in the facilitated group compared to 16 in the self-organizing group.

Comparison	Main results
Standard care (n=45)	The online support program realized significant changes to their blood pressure, cholesterol levels and smoking status compared with the standard care group but there was no statistically significant difference for physical activity.
Pairs (n=12) of students used standard, computer-based word processing software and contacted their mentors by phone for feedback	Google Docs group had better overall manuscript quality (mean Six-Subgroup Quality Scale (SSQS) score (SD) = 75.3 (14.21) vs. control group (mean SSQS (SD) = 47.27 (14.64) (p = 0.0017). Participant satisfaction (SD) was higher in the Google Docs group (4.3 (0.73) vs. control group (3.09 (1.11)) (p = 0.001) (5-point Likert scale). Control group had fewer communication events (SD) with their mentors vs. Google Docs group (0.91 (0.81) vs. 2.05 (1.23) (p=0.0219)
Participants (n=25)***** had access to a wiki without a moderated learning community (self-organizing community). In the self-organizing community, community members were required to analyze their own stories and share their stories with others.	There were no differences between the communities, except on the teaching presence subscale of direct instruction, where the facilitated community was rated significantly higher. Nurse educators in both communities significantly increased their own perceived leadership practices (The Leadership Practices Inventory) and perceived levels of empowerment (structural (Conditions of Work Effectiveness Questionnaire-II) and psychologic (Psychological Empowerment Instrument). Educators in both learning communities identified that their communities included the elements of teaching, cognitive, and social presence (Community of Inquiry Instrument). Given increases in empowerment levels, it was determined that both online learning communities could be considered empowering environments.
bPBL without wiki support (NB: more than one control existed in this study. other controls: cPBL, bPBL with chat support, bPBL with an interactive diagnostic context	Self-administered questionnaires revealed the following results: 1- Learning effect: wikis significantly reduced the perception of PBL case difficulty compared to chat and interactive diagnostic context. (No difference of wikis on other aspects: acceptance of the case's difficulty; feeling to have covered everything; preparedness for the exam; right diagnosis; number of right answers in the self-test; 2- Knowledge acquisition: perceived increased from pre to post significantly for all wiki groups. 3- Communication: wikis improved the perceived time to communicate, organization of work flow via communication, the density of communication, and the longevity of information communicated. 4- Collaboration: No significant perceived differences between wikis and other PBL groups; however, Chat improved perceived collaboration significantly. 5- Satisfaction: significantly increased with the bPBL with wiki support. 6- Wiki groups show significantly lower diagnostic selectivity; lower knowledge about diagnostic costs and lower knowledge about adequate diagnostic steps. 7- Wikis support 3 of the 7 steps in PBL: hypothesis formation; documentation of results; and working on tasks

7

Wikis to Facilitate Patient Participation in Developing Information Leaflets: First Experiences

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Abstract

Objective: Although patients have gained a wealth of experienced based knowledge they are usually not involved in the development of patient information. We sought to determine the technical feasibility of wikis in generating dynamic patient information leaflets with participation from patients and healthcare professionals and identified barriers and facilitators for wiki use.

Methods: An open wiki for patients receiving intrauterine inseminations and a closed wiki for patients receiving in vitro fertilization at one Dutch university clinic were used. Feasibility was assessed by analyzing logging data, content and users' experiences and expectations. The latter were addressed by means of semi-structured interviews, which were also used to identify barriers and facilitators to wiki use.

Results: Both patients and professionals worked on the information simultaneously, not hindered by time or location restrictions. The open IUI wiki was visited by 2,957 and the closed IVF wiki by 424 users. Twenty-eight barriers and 14 facilitators for using the wiki were identified.

Conclusion: Wikis are promising tools to improve patient participation in the creation of patient information. Future projects should aim to increase active use of wikis by testing interventions based on the wide spectrum of barriers and should evaluate the quality of the content produced.

Introduction

The Internet has changed the way in which information is presented and circulated. Within healthcare, digital information has become even more important than traditional hard-copy leaflets [1,2]. In the United States, 83% of all Internet users search online to find health-related information [3]. Moreover, patients not only use the Internet to find information, a growing number of patients also connect with peers on disease-specific online support groups such as PatientsLikeMe [4], on blogs and other social networks like Twitter and Facebook.

However, the almost unlimited availability of, and easy access to health- or disease-related information has a downside. First, it is often unclear whether information on the Internet is reliable and complete [5,6]. Second, information may be conflicting. If so, it will confuse patients and hinder the beneficial impact that information can have [7]. Third, finding miserable or sad personal stories on the Internet may cause insecure feelings in patients or may cause unnecessary suffering [8].

Realizing that complete and reliable information is essential, it seems a missed opportunity that patients are usually not involved in the draw-up of patient information [9-11]. They have gained a wealth of experience-based knowledge during their care process and are not for nothing described as 'experts of their own field' [12]. As a result, they are capable par excellence of estimating patients' information's needs and explaining procedures in layman's terms.

Nowadays, Internet offers solutions to enable patient participation. More specifically, due to Web 2.0 technologies, collaborative writing applications such as Wikis, Google docs and Google Knols have been developed. In recent years, they have become increasingly popular, also in the healthcare sector [13]. The best example of a collaborative writing application is probably a wiki, which enables online documents to be edited collectively [14,15]. Many Internet users use Wikipedia, a wiki with 22 million articles in 285 languages and as many as 362 million visitors per month [15,16]. One of Wikipedia's key features and maybe success factors is that the wiki is open, which means that everyone has access and can edit the information. Wiki software makes continuous peer review possible, which results in improved quality [15,17]. Furthermore, it is expected that the use of wikis in healthcare can reduce costs [18]. Scientists and professionals already use wikis to develop genetic databases, for instance on Wikigenes [19]. Wikis have also been used successfully in the field of medical education [20-22], which resulted in a feeling of empowerment among public health students participating in a study performed by Cobus (2009) [23]. As far as our knowledge reaches, wikis have never been used to develop patient information leaflets. Infertile patients seem to be a suitable population to explore the creation of information material using online collaborative writing applications. They have grown up with the Internet and are mainly average or highly educated [24-26]. Therefore, they will most likely not be hindered by barriers to wiki use such as complexity of wikis or other technical issues, that have been described as an important barriers to wiki use in the medical domain [27-30]. Furthermore, the Internet

already is the most important source of medical information for infertile patients, after books and healthcare professionals [26], but the quality of online infertility resources is often poor [31-33]. Interestingly, Infertile patients rank reliability of information as the most important issue for patient-centered care [34]. In hypothetical scenarios, infertile patients would accept less successful treatment(s) if they could possess information of higher quality [35]. Furthermore, current infertile patients wish for additional information like practical implications of infertility treatment for their work, side effects of medication use and success rates of treatment [36-38].

As the use of wikis is a novel approach to the creation of patient education materials, the aim of this study is to (1) evaluate the technical feasibility of wikis in developing dynamic patient information leaflets with participation from patients and health care professionals and (2) to identify the barriers and facilitators for using wikis for this purpose.

Methods and procedures

Study design and setting

The target population for this observational study consisted of Dutch infertile patients who received one the following fertility treatments: homologous IntraUterine Insemination (IUI), In Vitro Fertilization (IVF) or IntraCytoplasmic Sperm Injection (ICSI). In the Netherlands, a total of 17,770 fertility treatment cycles is performed each year [39]. Treatment is provided by general hospitals (IUI) and 13 IVF licensed clinics (IUI, IVF and ICSI). The Dutch national healthcare system reimburses all IUI cycles and the first three IVF and ICSI cycles.

To determine the feasibility of wikis in generating dynamic patient information leaflets and to identify barriers and facilitators, two types of wikis were examined: (1) an open wiki named 'IUI wiki' which was open for any Internet user and (2) a closed wiki named 'IVF wiki' that was open for a specific group of patients treated at an academic IVF clinic. The open wiki type was selected because it is known that only 13% of online community visitors in the US (e.g. Wikipedia) is considered to be a 'creator', that actually makes contributions [40]. Since the number of contributors to a wiki will probably be even lower, many visitors may be needed for a successful wiki. Although IUI wiki was open and the information could be viewed by anyone, registration was needed before information could be edited. The closed IVF wiki was selected to provide the users a private environment. As infertility has been surrounded by taboos and stigmatization [41,42], an open wiki could probably deter patients from participation. Furthermore, infertile patients have expressed positive experiences with a closed (password protected and hospital related) IVF portal [43].

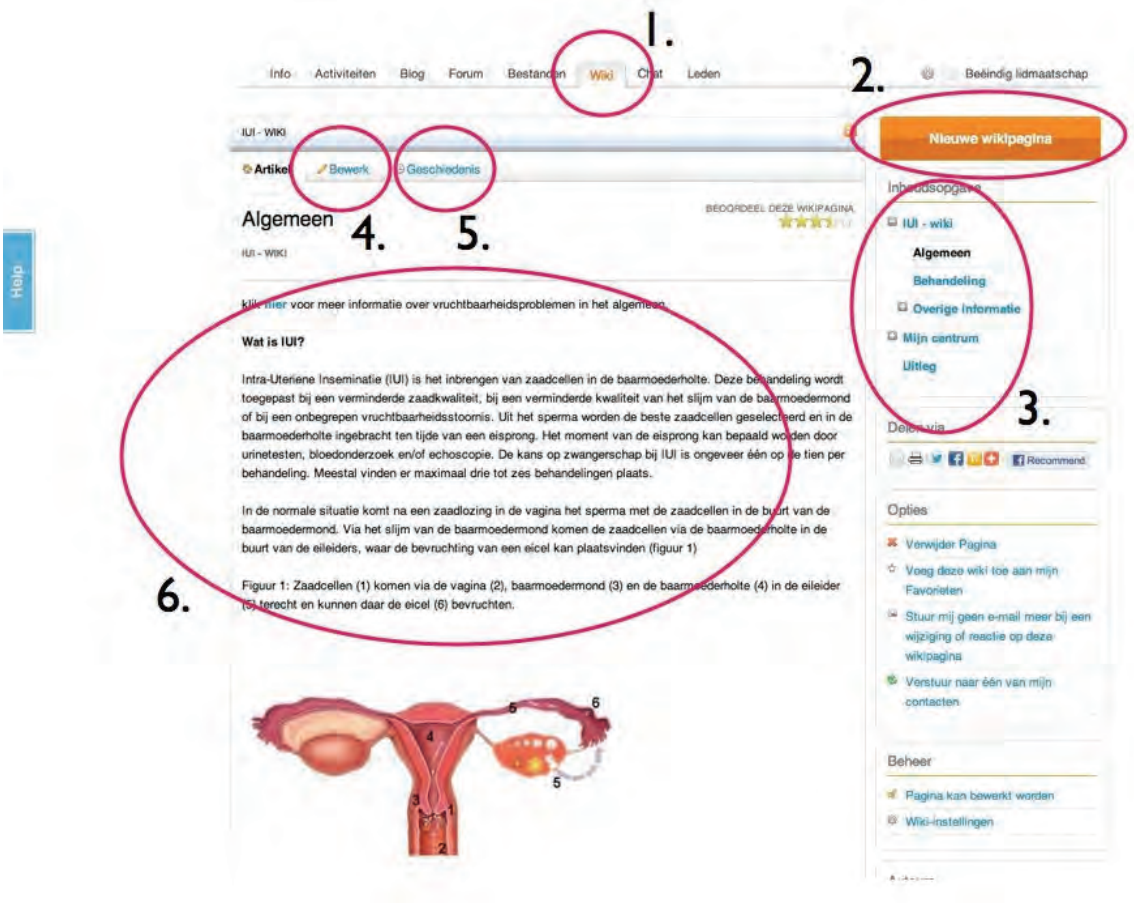
Wikis

Both wikis were provided by MijnZorgnet, a Dutch non-profit health care organization that offers an online platforms for patients, their relatives and health care professionals to connect, share information and communicate [44]. It consists of online environments (all located on the

MijnZorgnet website) that are called 'communities'. They are equipped with several features such as a blogs, wikis and the ability to share documents. The wikis were ready for use and no technical issues were expected since MijnZorgnet has been used successfully in the past [45]. MijnZorgnet assures privacy and data protection and works in accordance with the Dutch Personal Data Protection Act. Since the IVF clinic collaborating in this study had already made a MijnZorgnet community for their patients, we created IVF wiki on this community. For IUI wiki, a new community was created.

Both communities contained eight main tabs, which made quick and easy navigation possible. Figure 1 shows a screenshot of the IUI community including all features. Registration for the wikis was possible using "DigiD", a personal code provided by the Dutch government to ensure secured access to all governmental institutions.

Figure 1. Screenshot of the IUI community (In Dutch)



Wiki management

Managers (two nurses and two physicians specialized in fertility care) received e-mail notifications for every update, allowing them to intervene in the situation that a user would add misleading or incorrect information. Both users and managers were able to add, modify and remove content (including photos and videos). They could also compare wiki pages. Only managers were able to reset pages to a previous version and to remove users.

Basic wiki content

IUI wiki

For IUI wiki, which was part of the newly created IUI wiki community and not affiliated to a clinic, our aim was to use starting content that was created corresponding to the patients' needs. To do so, twelve couples visiting a large IVF licensed clinic in the Netherlands were invited to fill in an online questionnaire to gain insight in the priority (five-point Likert scale) of different IUI topics found in five official Dutch patient leaflets on IUI. Respondents were also invited to suggest new topics. Ten couples filled in the questionnaire, and the most frequently mentioned topics (n=10) were added to the wiki on different pages. The ten couples were also invited to help adding starting content for each topic. This was done prior to the official launch of IUI wiki.

IVF wiki

For IVF wiki, a hospital-based approach was used to determine starting content for the wiki. Based on the already existing hospital's patient information leaflets on infertility, two professionals working at the division of reproductive medicine added condensed information. All information was combined on one wiki to present it in an organized way.

Data collection

To raise awareness among patients and professionals and to persuade them to make contributions, an online and offline strategy were used simultaneously.

IUI wiki

Since the IUI wiki was aimed at all patients in the Netherlands suffering from infertility, we sent postcards with information about IUI wiki to all Dutch hospitals providing IUI (n=85). The mailing was directed to gynecologists, along with a personal letter inviting them to hand out postcards to patients. The Dutch Patients' Association for Infertility 'Freya' allowed us to add invitations in their monthly magazine and to Freya's homepage. Furthermore, three popular Dutch patient websites on infertility allowed us to add a link to IUI wiki. Also, a Twitter account was created to invite patients via tweets. Finally, professionals were contacted personally by email and were invited to write a blog on the IUI community.

IVF wiki

Patients treated at a large IVF-licensed clinic were informed about IVF wiki by flyers and posters in the waiting room. We also encouraged patients to visit the wiki via the online forum on the IVF community. Gynaecologists and nurses working at the clinic were informed about the project during a team meeting. They were asked to participate in the project and to encourage their patients to visit the wiki.

Time schedule

To avoid any confusion among patients or professionals, a serial approach for the two projects was used. IUI wiki was open from July 5th, 2010 to April 4th, 2011 and IVF wiki from June 6th, 2011 to April 2nd, 2012. The duration of the projects was selected since strongest growth for a wiki is expected in the first eight months [46].

Evaluation

The feasibility of the wikis was assessed by evaluating their use, content, and user's experiences (research objective 1). Since there are no comparable studies defining criteria for feasibility, we used the following two criteria for 'feasible': (1) At least 1 patient and 1 professional that contributed and (2) positive users' experiences. These criteria were selected since they are the minimum criteria to create a patient information leaflet without a wiki. We also identified barriers and facilitators to wiki use (research objective 2). We obtained logging data and performed in-depth interviews with patients and professionals.

Use

Logging data were analyzed to get insight in the use of the wikis, and the popularity of different pages. We retrieved server data about the total number of unique visitors, the number of times they logged on to the wiki (sessions) and the total number of pages that were viewed. This was done at the end of the research period. Individual users were recognized using tracking cookies and were linked to users' profiles if possible. Visits by search engines were excluded automatically. We also determined the number of times that users actually contributed to the wikis.

Content

Using the wikis' history function, contributions (revisions) made by professionals and patients were counted manually. The following features were analyzed: (1) number of revisions, (2) type of action (e.g. adding, removing, replacing, commenting) and (3) content (which content was modified e.g. information, typo's, spelling etc).

Users' experiences including barriers and facilitators

User experiences and expectations of patients and professionals were addressed by means of in-depth interviews. Based on the model for implementation of Grol and Wensing, we developed an interview guide that consisted of four domains: Characteristics related to the patient, (e.g.

motivation for registration to MijnZorgnet), professional (e.g. expectations), intervention (e.g. user-friendliness and registration procedure) and context (e.g. organizational aspects) [47]. The interview guide is available on request. Respondents were interviewed face to face or by telephone by one researcher (TB). All interviews were transcribed verbatim. Subsequently, two researchers (TB and ND) individually performed a thematic content analysis to determine barriers and facilitators [48-50]. All barriers and facilitators were derived from the data. TB and ND discussed the results together, until consensus was reached. Patients were recruited via direct messages sent via the community, or were invited by nurses. We intended to interview all patients and professionals who at least logged on to the wiki once. In addition, we aimed at interviewing professionals and patients who had not used the wiki, but indeed knew the wiki existed. Totally, nine patients and five professionals were interviewed.

Results

Use

Table 1 shows the usage statistics for IUI wiki and IVF wiki. The open IUI wiki was visited by 2,957 unique visitors who viewed 2.3 pages on average. The closed IVF Wiki was visited by 424 unique visitors, who viewed 23.8 pages on average.

Table 1. Visitors and page views

Variable	IUI wiki	IVF wiki
Wiki Users (unique visitors)	2,957	424
Wiki Sessions (visits)	3,456	1,907
Wiki (page) Views	6,902	10,109
Wiki pages	21	66
Page views per user (mean)	2.3	23.8

IUI and IVF wiki were open for nine and ten months, respectively

Content

Our invitation directed to the ten couples to help create the starting content of IUI wiki (before the official launch of IUI-wiki), did not result in any new contributions. During the official research period, five patients and five professionals have been active on IUI wiki. On average, they accounted for two and 12 revisions respectively. No comments were posted. On IVF wiki, 11 patients and four professionals were active during the research period. On average they were responsible for 3 and 38 revisions. Patients added 6 comments including experiences with medication and other comments with general questions and/or remarks, e.g. where to find information about medication. Patients added three pages about instructions how to use a wiki, one page about the policy regarding transferring embryo's to the uterus, one page containing instructions to use medication, one page containing general information about the university hospital's pharmacist and one page about reimbursing travelling costs. Remarkably, professionals who were active on IVF wiki added pages about IUI treatment. Further statistics about wiki content and activity are presented in Table 2.

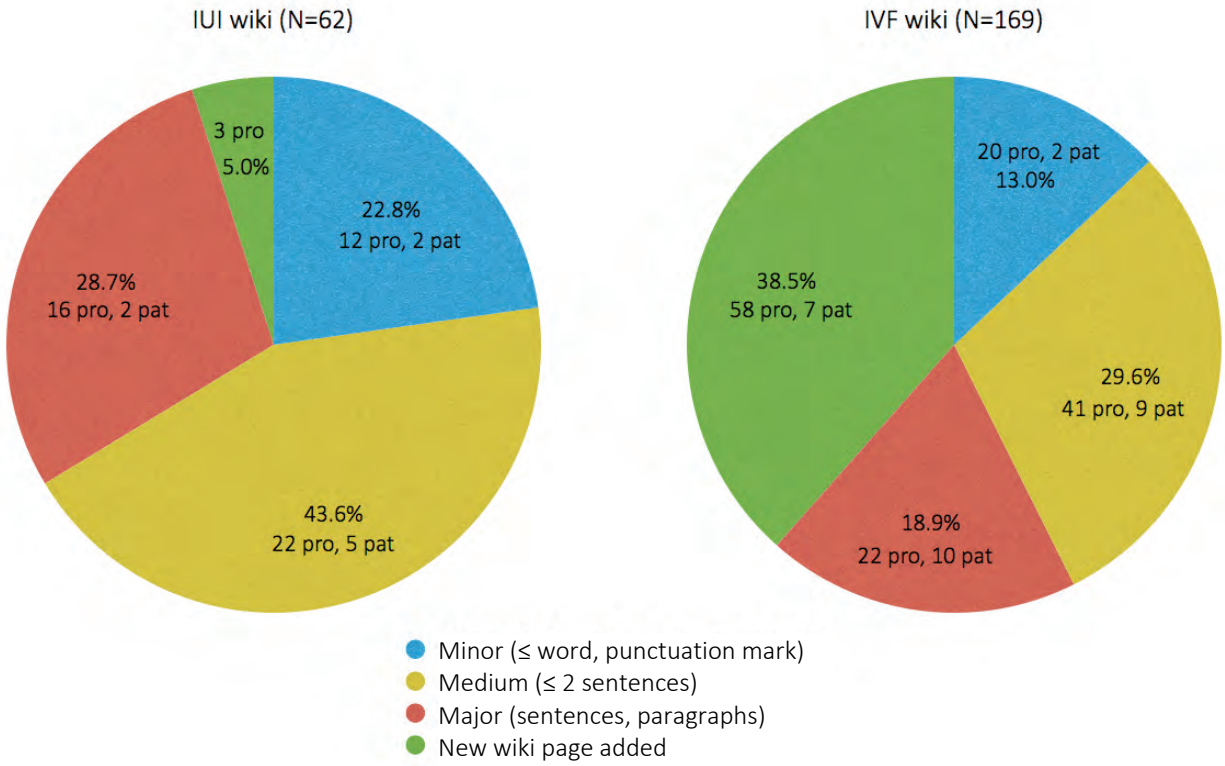
Table 2. Wiki content and activity

Variable	IUI wiki	IVF wiki
Pages added by patients	0	7
Pages added by professionals	3	58
Active patients	5	11
Active professionals	5	4
Revisions by patients	9	32
Revisions by professionals	60	152
Comments by patients	0	6
Comments by professionals	0	3

IUI and IVF wiki were open for nine and ten months, respectively.

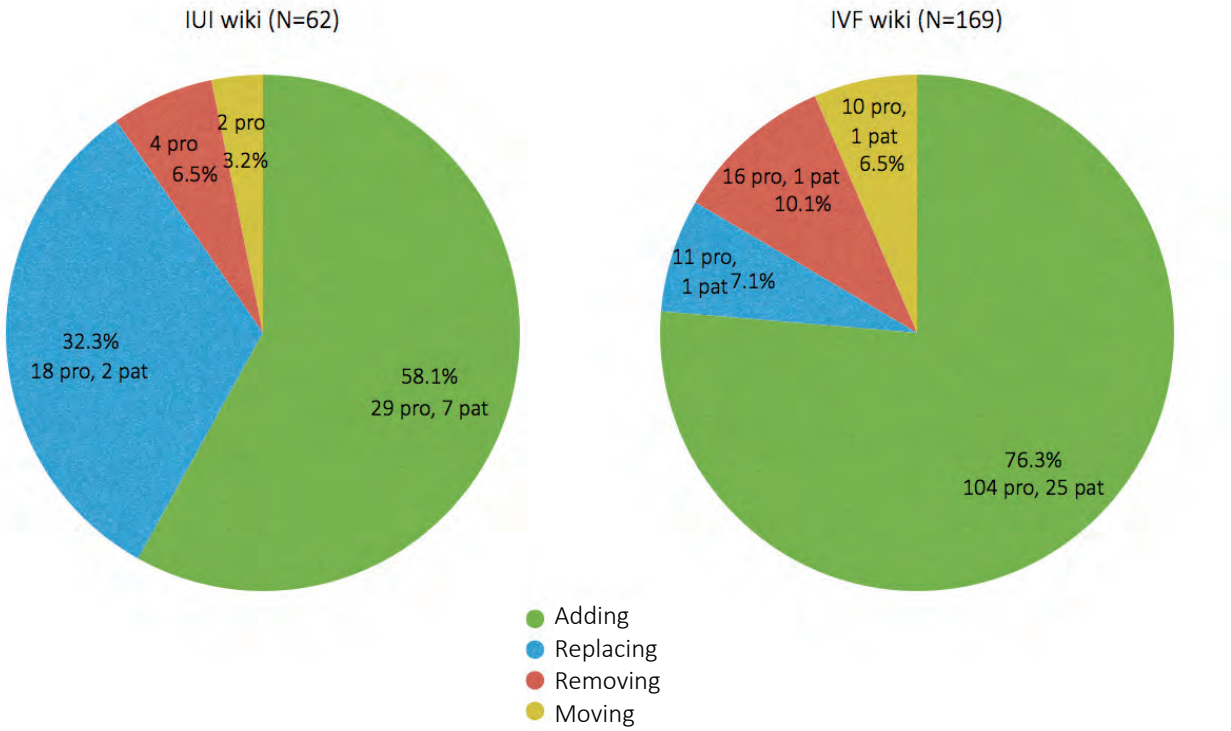
After excluding seven and 15 revisions without any visible changes on IUI and IVF wiki, respectively, a total of 62 and 169 revisions were analyzed for IUI and IVF wiki, respectively. Figure 2 shows the quantity of contributions. On IUI wiki, most contributions (43.6%) were medium size changes (≤ 2 sentences). Most contributions on IVF wiki consisted of adding wiki pages (38.5%) and medium size changes (29.6%). Figure 3 shows the different types of contributions on IUI and IVF wiki. On both wikis, most actions consisted of adding content (58.1% for IUI wiki and 76.3% for IVF wiki).

Figure 2. Quantity of contributions on IUI and IVF wiki



Quantity of contributions for IUI and IVF wiki, % for patients and professionals combined. Numbers provided for professionals (pro) and patients (pat)

Figure 3. Type of contribution on IUI and IVF wiki



Type of contribution on IUI and IVF wiki. % for patients and professionals combined. Numbers provided for professionals (pro) and patients (pat)

On IUI wiki, 32.3% of all contributions consisted of replacing information. Patients revised information on wiki pages about IUI treatment (e.g. readability) and pages with specific information for different clinics (e.g. treatment policy). On IVF wiki, patients modified information on wiki pages about advises (lifestyle advises), pharmacy (availability of medication), parking and reimbursement of traveling costs, and pages about IVF treatment (practical advises about the use of mediation). Furthermore, patients added four hyperlinks.

Users' experiences including barriers and facilitators

Nine patients and five professionals were interviewed. Patients received or had received IUI (n=5), IVF (n=3) or both (n=1). All professionals provided both IUI and IVF treatment. For IUI and IVF wiki, a total 28 of barriers and 14 facilitators were identified (Tables 3 and 4, respectively). No facilitators concerning the individual (patient and/or professional domains) were recognized.

Table 3. Barriers for wiki use

	Barrier	Patients	Professionals
Barriers on the domain 'intervention':			
1	Not enough activity	*	
2	Too many personal stories instead of information	*	
3	Incomplete information	*	
4	Information is not unambiguous	*	
5	Don't trust the quality of information	*	*
6	No added value compared to traditional leaflet	*	
7	Hard to find the wiki in the community	*	
8	Principle of using a wiki unclear	*	
9	Inefficient to work on traditional leaflet AND wiki information		*
10	Lacking instruction about the wiki	*	
11	Lay out is unprofessional	*	
12	Navigation is difficult	*	
13	Don't like the openness of IUI wiki	*	
14	Issus with registration/logging in (DigiD)	*	*
Barriers on the domain 'patient':			
15	Prefers other ways of communication e.g. email	*	
16	Emotional/stress	*	
17	Didn't like the way he/she was informed about the project	*	
18	Beliefs privacy is not protected	*	
19	Who am I to change something?	*	
20	Fear e.g. because professionals are watching	*	
21	Don't speak Dutch well enough	*	
22	Not the right moment (too early or too late)	*	
23	Haven't heard about the project in time	*	
24	Beliefs it's not the right population to use a wiki	*	
Barriers on the domain 'professional':			
25	No incentive to join: Patients never asked me to join		*
26	Too many other things		*
Barriers on the domain 'patient/professional':			
27	No need to communicate with (peer) patients	*	*
28	Not enough Internet skills	*	

Total: 28 barriers

Table 4. Facilitators for wiki use

	Facilitator	Patients	Professionals
	Facilitators related to the domain 'intervention':		
1	Fast communication and updating information	*	*
2	Information presented in a formal way	*	
3	Peer support	*	
4	Good Quality of information on the wiki	*	*
5	Good Reliability of information on the wiki	*	
6	Completeness of the information on the wiki	*	
7	It saves time (less phone calls by patients)		*
8	It safes (editorial) resources: less patient leaflets to print		*
9	Access restricted to patients and professionals	*	*
10	Openness: Access for everyone	*	
11	Dynamic information and input from multiple people	*	*
12	Secured registration process with DigiD	*	*
13	Practical procedure	*	
14	Wiki looks very good	*	

Total: 14 Facilitators

Barriers

Intervention domain

In the intervention domain, 14 barriers were identified. Four patients experienced that the navigation on the wiki was too difficult. One respondent described this as follows:

> *"I can get annoyed because everything flips open and disappears at the bottom"*

Furthermore, patients stated that the lay out was unprofessional or not medically enough. Other patients experienced troubles finding the wiki or the community. Privacy and registration were also experienced as barriers, mentioned by three patients and one professional. A patient described:

> *"I believe it is a difficult match.. ehm.. A governmental ID.. That I have to use for accessing a health care page"*

Some patients believed that the information on the wiki was incomplete, that there were too many personal stories or that there was no added value compared to a traditional leaflet.

Individual domains

In the patient and professional domains, 14 barriers were identified. Three patients mentioned restraints. They hesitated because they did not consider themselves as the right person to change wiki content or because professionals could see their work. Others did not understand the principle of the wiki, did not like the openness of IUI wiki or preferred communication via other channels (i.e. email). One patient and one professional did not have the needs to communicate with patients. The latter stated that patients had never asked for it. Another professional said that

there was no time to be actively involved on the wiki and that other (clinical) tasks had higher priority.

Facilitators

Intervention domain

In the intervention domain, 14 facilitators were identified. Three patients and one professional stated the quality of the content was a facilitator to use the wiki. Furthermore, three other patients and one professional favored the use of DigiD. It ensured secured access. Other patients mentioned the completeness of information. Two patients favored this new approach because there was input from multiple persons. Two patients mentioned fast communication whereas other patients found that the wiki looked very attractive. One professional believed that using a wiki saves time and editorial resources. It appeared that the openness of the open IUI wiki was a facilitator. Remarkably, the intimacy of the closed IVF wiki was also identified as a facilitator.

Discussion

Main findings

In this study, we used a unique approach to create online patient information with participation from end users: patients. Patients and professionals worked on the information simultaneously, not hindered by time or location restrictions. Furthermore, the open IUI wiki was visited by 2,957 users and the closed IVF wiki by 424 users. Therefore, we conclude that wikis are promising tools to stimulate patient participation in the creation of patient information.

Regarding the finding that only five patients (1.8%) actively contributed to IUI wiki and 11 patients (2.6%) to IVF wiki, the number for active participation seem to be low. However, the numbers for active contributors to Wikipedia are notably lower (0.02-0.03%) [51]. Also, it is known that a relatively small group of enthusiastic users accounts for most contributions on wikis [15]. On the closed IVF wiki, the number of page views per user was ten times higher than on the open IUI wiki, which makes it likely that closed wikis work better for infertile patients. However, the design of our study did not allow us to make final conclusions about the influence of open and closed wikis. Therefore, this should be addressed in future studies.

Patients were responsible for only 13 and 17% of all revisions on IUI and IVF wiki, respectively, implying less active involvement than professionals. Several identified barriers can explain these lower levels of participation by patients. We identified that restraint can be a barrier for patients. Possibly, they hesitate to make contributions because their physician may be watching. Another relevant factor could be that patients have never been invited to make contributions to patient information material before.

On IVF wiki, four professionals were responsible for 152 revisions. Although some were highly enthusiastic and favored this new approach, over 50 professionals work at the clinic, which means

that only 8% of the professionals made contributions to the wiki. The barriers 'no time' and 'no need' to participate in the wiki supports this. Following the professional who stated that it was inefficient to keep two information sources up to date, we believe that removing the conventional patient information leaflet would have resulted in more incentives to use the wiki and probably a higher level of participation.

On both wikis, the main part of all actions consisted of adding content, whereas only a small part consisted of removing content. These results correspond to a study about the wiki usage by students that found that that 83% of all editorial actions consisted of adding content and 15% of removing content [22]. Apparently, it is easier to add information to a wiki than to remove it: people may hesitate to remove or modify another person's work. As this can theoretically result in too long wiki pages with too much text, a solution could be to allow specific people to moderate pages.

Twenty-eight barriers and 14 facilitators for wiki use were identified. Interestingly, some patients experienced the personal DigiD required to login to the system a barrier, whereas other patients experienced this as a facilitator. Apparently, the ID that is usually used to pay taxes and is provided by the Dutch government can cause safe feelings in some patients whereas other patients can believe it is strange to use DigiD. The latter believed that herewith their privacy was in jeopardy. Also, patients found that this procedure was unpractical. Varying experiences with DigiD were also found in a study involving an online community for infertile patients [45]. Therefore, it is important for future projects to search for the optimal combination of the high security standards and a user-friendly login procedure.

The quality of wiki content was a facilitator for using the wiki. It was believed that 'dynamic' information resulted into more complete and better information compared to 'static' conventional leaflets. Interestingly, quality of content was also a barrier for using the wiki. As anyone could modify wiki content it was believed that people could add incorrect information, which could mislead other people. A solution for future projects can be to mark recently added content until responsible experts have approved it.

Other research

Research about professionals and patients that used wikis to collaborate is rare. In a study performed in the field of pulmonology, wikis have been successfully used to create Asthma Action Plans (AAPs) [52]. In this study, 20 professionals and 21 patients accounted for an average number of 646 contributions per week. Although these numbers are promising, it should be considered that all participants had incentives to login to the wiki; it was needed to login to the wiki once a day and every participant received e-mail reminders daily. In the present study, there were no such incentives to participate. This could explain the limited numbers of contributions in the present study. Furthermore, our findings only partially correspond to a recent Dutch study that

showed that wikis are feasible tools to determine relevant patient information to develop guidelines. During seven months of access, 298 patients added and prioritized 289 recommendations [53]. However, no professionals participated in this study and therefore it is difficult to compare the results at all levels.

Strengths and limitations

The main strength of the present study is that patients were actively involved in the creation of patient information. They were able to collaborate with professionals, incorporate additional topics experienced as being relevant during their care process, and describing them in layman's terms. This can be beneficial for future patients. Several limitations can be discussed. A first limitation encompasses the scope of our study. Following our approach, we were interested in determining the feasibility of using a wiki for engaging patients in the development of information. Although we did not determine the quality of the wiki content, one could argue that any contribution would improve the quality of the information since the contributor is missing information or is otherwise unsatisfied. However, getting insight in the quality of wiki content prior to safe implementation in healthcare is important and we therefore recommend future researchers to investigate this. It would also be relevant to study the extent to which the content generated reduces the number of shortcomings experienced by infertile patients, and the impact wikis have on future patients' health care experiences and quality of care. Furthermore, economic evaluations can demonstrate the cost effectiveness of wikis in health care.

A second limitation of the study is that we were unable to locate all nonusers of the wiki. As a result, we may have missed relevant barriers. Third, it is important to note that we were unable to correct for visits and sessions by one researcher, which were related to this research project. As a result, the exact numbers for visits and sessions could slightly differ. Since the frequency of these visits was low, we assume that this has not significantly biased the results. Finally, it may be difficult to predict the suitability of wikis for other patient groups based on the present study. However, we expect that wikis will be suitable for other populations since Internet use and the use of online tools is increasing [54] and online portals are increasingly used by patients [55].

Conclusion

We showed that it is technically feasible to use wikis to stimulate patient participation in the creation of patient information and we successfully identified a spectrum of barriers and facilitators for the implementation or operational use of wikis. Future projects should aim to increase the active use of wikis by testing interventions based on these barriers and should evaluate the quality of the content produced and its effects on patient-centeredness. Implementers should use a user-friendly design and eliminate barriers related to the interface.

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8

Evaluation of Patients' Questions to Identify Gaps in Information Provision to Infertile Patients

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Provisionally accepted.

Abstract

Objective: The objective of this observational study was to identify gaps in provided written patient information (supply-driven) at an infertility clinic, by systematically analysing questions raised by infertile patients (demand-driven) on a forum or during phone and group consultations.

Methods: We did this (1) by identifying themes that patients undergoing Medically Assisted Reproduction asked questions about and (2) by determining to which extent the questions asked by patients could not be found in the information leaflets provided by the clinic. Content analysis was used to identify themes and the extent to which existing patient information leaflets did not provide answers. A total of 193 questions were included and 24 different themes were identified (e.g. blood loss during treatment, side-effects of medication and use of medication).

Results: Half of the patients' questions could not or only partially be answered using the conventional patient information leaflets (51%).

Conclusion: Health care providers should realize that the information they provide does not necessarily all demand-driven information needs. Therefore, involving patients in the creation of patient information for instance through an approach such as we evaluated, will provide insight into informational needs of patients, and will help health care providers to keep their supply-driven information up-to-date and patient-centered.

Introduction

High quality information about their treatment is of key importance to patients. It helps them to be well-prepared, participate and make better decisions. Moreover, if patients are well-informed it may lead to a more mature patient-doctor relationship, higher rates of compliance and better health outcomes [1-3]. Moreover, written information can serve as a reminder of information already provided. Traditionally, caregivers provide information through face-to-face encounters and patients' information leaflets. This is usually a combination of supply-driven information (e.g. a doctor spontaneously giving an information leaflet to a patient) and demand-driven information (e.g. a patient asking information about medication).

Currently, the Internet has become an important source for medical information [4]. Patients can find information on online patients' communities, discussion forums, wikis such as Wikipedia [5] and many other online sources. Especially for younger generations of patients such as infertile patients, the Internet is decisive [6,7]. For them, it is the primary source of medical information, after books and health care professionals [8]. The downside of searching for information on the Internet is that it can be contradictory, unreliable, and incomplete [9]. This can cause insecure feelings and unnecessary suffering [10] and might hinder the beneficial aspects that being well-informed can have [11]. Moreover, since research shows that the quality of online infertility resources is often poor [12-14], it is important for healthcare providers to offer high quality information to their patients, whether it is online or offline. This is particularly important in fertility care, because incomplete and conflicting information is a problem experienced by infertile patients [15]. Moreover, information provision is of great importance to them. In hypothetical scenarios, infertile patients would even be willing to accept even less successful fertility treatments if they could receive information of higher quality [16]. Furthermore, infertile patients ask nowadays for additional information such as the practical implications of infertility treatment in relation to their work, side effects of medication use and success rates of treatment [15-18).

In order to meet infertile patients' demands, we reasoned that easy and innovative ways of improving patient information or keeping it up-to-date were needed. Therefore, the objective of this study was to identify gaps in written patient information provided (supply-driven) at an infertility clinic, by systematically analyzing questions raised by infertile patients (demand-driven) on a forum or during phone and group consultations. We did this (1) by identifying themes that patients asked questions about and (2) by determining to which extent the questions asked by patients could not be answered using the information leaflets provided by a fertility clinic.

Materials and methods

Design and setting

In this observational study, we compared the questions that infertile patients asked (demand-driven information) with the provided patients information leaflets provided (supply-driven). The target population consisted of Dutch infertile patients who received one of the following fertility treatments: homologous IntraUterine Insemination (IUI), In Vitro Fertilization (IVF), IntraCytoplasmic Sperm Injection (ICSI) or Ovulation Induction (OI). In the Netherlands, a total of 21,164 treatment cycles [19] of Medically Assisted Reproduction (MAR) [20] are performed each year. The Dutch national health care system reimburses all IUI cycles as well as the first three IVF and ICSI cycles. For this study, a large university clinic in the eastern part of the Netherlands (Radboudumc university medical centre) was selected. This clinic performs around 1,500 IVF/ICSI cycles and 900 IUI cycles each year.

Sources of patient information

In this setting, written supply-driven information is provided through information leaflets. Demand-driven information is, amongst others, provided by (1) the clinic's online discussion forum; (2) phone consultations and (3) a patient education meeting (only for patients undergoing IVF/ICSI).

Patient information leaflets

Two patient information leaflets are available. Both are based on the clinical guidelines of the Dutch Association for Obstetrics and Gynaecology, and have been tailored to the clinic by nurses, medical specialists and communication specialists. Leaflets are revised if the clinic’s policies change. Every year, the list of phone numbers and addresses provided in the leaflets is checked and updated if needed. The first leaflet consists of 36 pages with general information about the clinic and brief information on different treatment options. It contains seven chapters: General Information; Information about reproduction including advice for couples; Fertility assessment, Treatment options; The clinic's team; Other information e.g. costs/insurance and contact information. The second leaflet consists of 40 pages with specific information on IVF/ICSI. There are six chapters: General information (e.g. indications); Pre-treatment (e.g. investigations); Treatment (e.g. procedures); ICSI; Additional information and information about the team. Furthermore, four sheets with systematic descriptions of the treatment schedules for IUI and IVF/ICSI are available for patients. Relevant information leaflets are offered to patients before starting the treatment. They are available in hard copy at the department and online (as PDF) via the clinic's website.

Online discussion forum

The clinic has an online discussion forum, which forms part of the clinic's online infertility community. Only patients treated at the clinic have access. Questions are primarily answered by nurses. They are being supervised and if needed, the questions are redirected to gynecologists and

embryologists. Secured access is assured by using "DigiD", a personal code provided by the Dutch government to guarantee safe access to all governmental institutions.

Phone consultation

Every morning (Monday to Friday) between 8AM-9:30AM, patients can call the clinic to ask questions about their treatment. Nurses are available to answer these questions and they also have access to the patient's electronic health record to provide specific personal information, e.g. dosage of medication.

Patient education meeting

A patient education meeting is compulsory for every new IVF/ICSI couple and takes place before couples start their treatment. It consists of a lecture with a digital presentation based on the patients' leaflets. A maximum of seven couples receive information about the general treatment schedule, as well as being shown how to use medication (e.g. self inject medication). Furthermore, they are informed about the preservation possibilities of oocytes, semen and embryos. During these meetings, patients can interact directly with the nurse and with each other, thus having the opportunity to get acquainted with the team and raise questions. The sessions last for two hours and are organized twice a week.

Data collection (Step 1)

We went through four operational steps in order to collect and analyze data systematically. We collected data on the online discussion forum and by attending phone consultation sessions as well as patient education meetings. Data collection and analysis were terminated when no new issues appeared to emerge.

Online discussion forum

All forums' threads posted between March and June 2011 were downloaded, anonymized and copied to a text file for further analysis.

Phone consultation

In February 2012, TB and AH were present during eight phone consultation sessions, capturing 113 questions. Nurses talked to the patients and informed the researchers about the patient's question after each call. No personal data such as names, addresses or birth dates were shared or registered with the researchers. We used an extraction table to extract per phone consultation the item's sequence number, patients' question(s) and date. Every question was added separately and written down as literally as possible. Furthermore, the information written down in the table was immediately verified by discussing it with the nurse, in order to make sure the correct question was written down and to prevent misinterpretations. Phone calls without patients asking questions (e.g. if a patient called to provide the result of a pregnancy test or change an appointment) were excluded.

Patient education meeting

A total of three patient education meetings were attended, by TB as well as AH in February and March 2012. The same table as for the phone consultation was used to write down every question separately. After the meeting, each question was discussed by the two researchers, in order to make one final list of items.

Data interpretation and coding procedures (Step 2 and 3)

All questions gathered on the online forum, during phone consultation sessions and patient education meetings were added to a spreadsheet program (MS Excel). Further analysis consisted of two steps. First, the theme for every item was determined. Second, the extent to which patient information leaflets provided an answer for every item was scored.

To arrive at the themes, two researchers (TB, AH) independently condensed each question, until a shortened version of the question remained, without losing core information according to the principles of qualitative content analysis described by Graneheim (2004) [21]. The same two researchers then independently selected themes for every question by performing a confirmative analysis using an existing coding tree with 44 themes. This coding tree was considered as relevant since it concerned general communication between infertile patients and healthcare providers [22]. However, not all themes were relevant for the present study, as the list included more than solely demand-driven communication, not all themes were relevant for the present study. The first 20 questions were discussed to guarantee coding reliability. Subsequently, assessment of the data collected during the phone consultation sessions, online forum and the patient education meetings was performed by reading the question and its related condensed unit, and subsequently cross-referencing patient questions in the current patient information leaflets. We defined 'findability' as the possibility to find the answer to a certain question in the two patients' leaflets. Five categories for findability were identified: (1) Yes: information fully available in leaflets, (2) Partially: the subject is mentioned, but the present information is not sufficient to answer the question, (3) No: no information at all available in leaflets, (4) Contact needed and no info available in leaflets and (5) Contact needed and partial info available in leaflets. Category 4 and 5 were created to distinguish between those questions where general information or specific individual information was requested. In the latter case, patients had to contact the department in order to get an answer, because information from their medical record was needed. In categories 1, 2 and 3, this was not necessary. Categories 2 and 3 were used to identify areas for improvement, since these categories all concern the ‘lack of information’ in the patient information leaflets. Finally, all disagreements in coding and findability were discussed and consensus was easily reached in all cases.

Reliability of data interpretation and coding

Cohen Kappa theory was used to determine the coding reliability for the theme assignment in step 1 and the findability in step 2. This coefficient was used to determine the inter-coder agreement for qualitative measures, since it was thought to be a more robust measure than simple percent agreement calculation and takes into account agreement occurring by chance. Values of 0.40-0.75 are rated as fair to good agreement, and values over 0.75 are rated excellent agreement [23].

Evaluation of results (Steps 3 to 5)

Results for the themes that were identified were presented in a table. The results for 'findability' were presented in graphs and bar charts.

Ethical approval

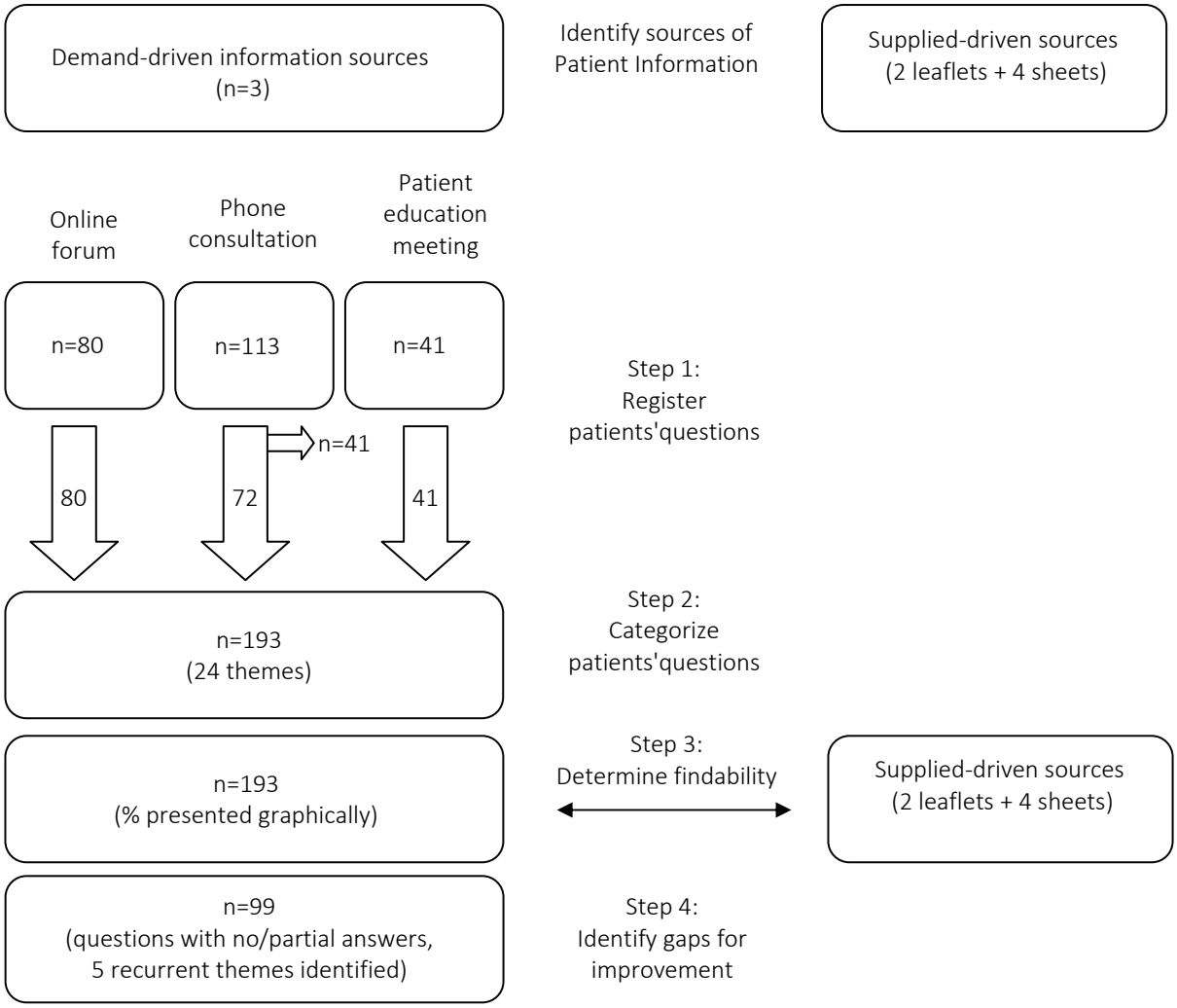
The institutional ethics committee reviewed and approved the study protocol, and concluded that our study was not subject to the Dutch Medical Research Involving Human Subjects Act. Since only anonymous data were collected, no permission was needed to use the data by obtaining informed consent. However, we informed patients beforehand that content could possibly be used for scientific purposes. Moreover, patients reserved the right to object against this.

Results

Sample

In total we collected 234 items, of which 193 were included in the study as being a question. Forty-one cases were excluded because they concerned phone calls without a patient asking a question, for example rescheduling an appointment. Figure 1 shows the number of questions that were included from the online forum, phone consultation and patient education meeting and summarizes the four operational steps that we have gone through.

Figure 1. Flow chart and four operational steps



Coding reliability

The kappa values for coding the correct theme were rated good to excellent (.83, .77 and .63 for the online discussion forum, phone consultation and patient education respectively) and the kappa values for determining findability of the answers in the leaflets was rated excellent (.88, .81, .80 for the online discussion forum, phone consultation and patient education respectively).

Themes

In total, 24 different themes were identified in these 193 questions. Table 1 shows all themes and the frequency in which they appeared. For six themes, questions were raised in all three sources.

Table 1. Frequency of themes on online forum, phone consultation and patient education meeting

Theme[a]	Online forum (n^b=80)	Phone consultation (n^b=72)	Patient education meeting (n^b=41)
Blood loss during treatment	15.0%	20.8%	-
Medication: Side effects	15.0%	6.9%	7.3%
Medication: Use/Application	12.5%	22.2%	36.6%
Quality oocyt/embryo/semen: Determination of quality	7.5%	1.4%	7.3%
Community: Accessing Personal Health Data	7.5%	1.4%	-
Quality oocyt/embryo/semen: Lifestyle advices	6.3%	11.1%	-
Schedule of treatment	6.3%	5.6%	34.1%
Medication: Preservation	6.3%	2.8%	4.9%
Asking for statement	2.5%	5.6%	-
Medication: Interaction with other medication	2.5%	2.8%	-
New treatment options or medication	2.5%	-	-
Other facts	2.5%	-	-
Success rates: combination with other medical conditions	2.5%	-	-
Psychological: Ask for support	1.3%	8.3%	-
Stock of oocyt/embryo/semen	1.3%	2.8%	9.8%
Alternative treatment options e.g. Acupuncture	1.3%	-	-
Community: Logging on	1.3%	-	-
Community: Other	1.3%	-	-
File (Health Record)	1.3%	-	-
Scientific research	1.3%	-	-
Success rates: after previous fertility treatment	1.3%	-	-
Success rates: age	1.3%	-	-
Failed treatment: Consequences future treatment	-	6.9%	-
Adverse effects after positive pregnancy test	-	1.4%	-

[a] Total: 24 themes.
[b] Number of questions asked by patients

Eighty questions were included from the online forum. The most recurrent themes were "Blood loss during treatment" (15%),"Medication: Side Effects" (15%) and "Medication: Use/Application" (12.5%). 72 questions were analyzed for the phone consultations. The most popular themes were also "Blood loss during treatment" (20.8%), and "Medication: Side Effects" (22.2%) but also "Quality oocyt/embryo/semen: Lifestyle advice" (11.1%). During the patient education meetings, the most popular themes were "Medication: Use/Application" (36.6%), "Treatment schedule" (34.1%) and "Stock of oocyte/embryo/semen" (9.8%). Example questions (translated from Dutch) for the most recurrent themes found within all three themes are:

Blood loss during treatment: *"Blood loss (four days of spotting) after embryo transfer: Should I continue using my medication?"* [Progesterone]

Medication: side effects: *"My wife started using medication [Treptorelin injections], how much blood loss can be expected?"*

Medication: use/application: *"My wife needs 300 units of medication but there are still only 250 units in the medication pen injector"* [What to do?]

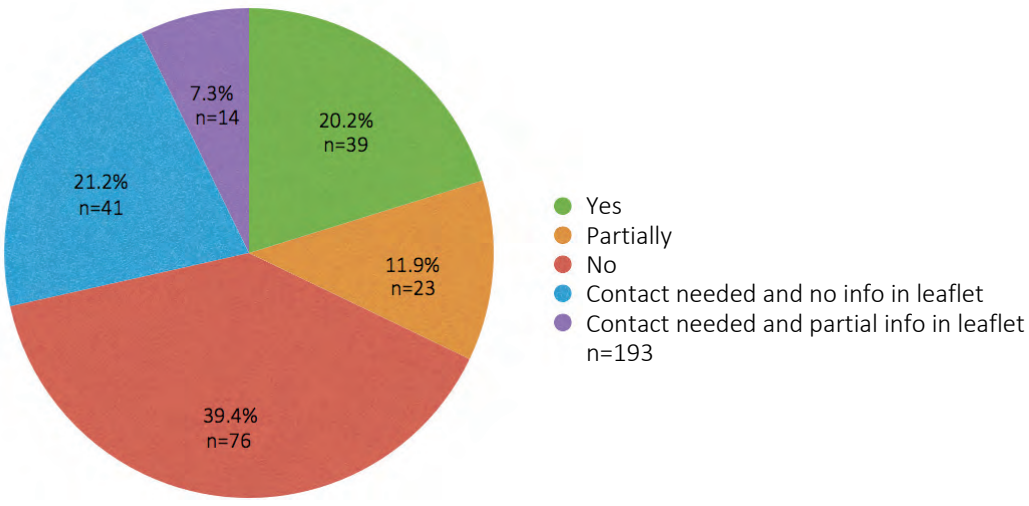
Quality oocyte/embryo/semen: Lifestyle advices: *"My husband is running a fever and is now on antibiotics. How will this affect his semen? Should we proceed [or stop] with this attempt?"*

Treatment schedule: *"We would like to go on a holiday. Is it possible to postpone the IUI treatment for one month?"*

Content of patient information leaflets

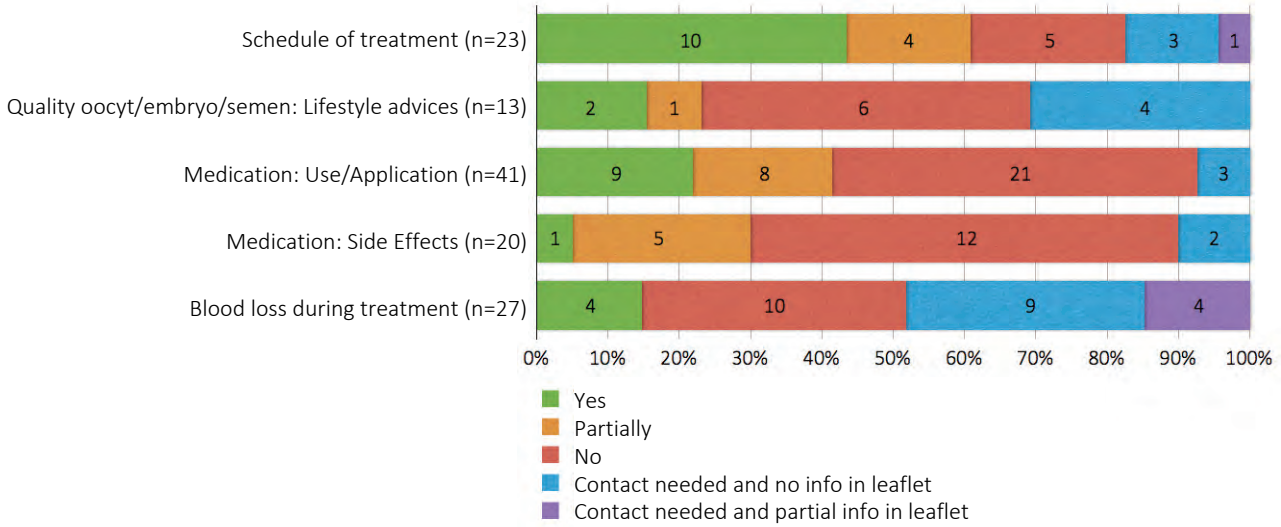
Findability was determined for the sample of 193 items, consisting of the included questions of the phone consultation, the online forum, and the patient education meetings. Figure 2 shows frequencies for the five findability categories. As there was a similar pattern for the three sources, the results were presented in one figure. For 39 out of 193 questions (20.2%), the patient information leaflet provided a complete answer. For 23 out of 193 questions (11.9%), an answer only partially available in the leaflet and for more than one third (76 of 193 questions, 39.4%) there was no answer found in the patient information leaflet. In all other cases, the patient had to contact a health care professional, e.g. "how much medication [Follitropin] should I use?" In 41 out of 193 questions (21.2%), the leaflet provided no information and for 14 out of 193 questions (7.3%) it provided partial information.

Figure 2. Findability of answers



Distribution across the findability categories was not comparable for all themes. For example, answers on 10 out of 23 (43%) questions regarding treatment could be found in the leaflets, compared to 1 out of 20 (5%) questions about the side-effects of medication. Figure 3 provides more detailed information about illustrative themes (> 10% of all questions).

Figure 3. Findability for individual themes



Discussion

Main findings

In this study, we used an easy and innovative approach to identify gaps in the patient information provided. We analyzed questions asked by infertile patients via different sources (private online forum, phone consultations and patient education meetings) and compared them to patient information that was provided by a Dutch infertility center specialized in IUI and IVF/ICSI. We revealed that patients ask questions about a wide range of issues (24 different themes) and that half of all questions (51%) could not or only partially be answered using the conventional patient information leaflets. The approach used is therefore a feasible approach of identifying areas of improvement and can be a first step towards improvement of supply-driven information provision.

Most questions asked by infertile patients concerned the themes blood loss during treatment, medication (side-effects and use) and the quality of oocytes/embryo/semen. This is comparable to other research, which shows that infertile patients mostly ask questions mostly about "current treatment" (47.1%) [24] and medication [15]. Health care providers can use the results of this study to further improve the completeness of the information that they provide to their patients. A clear explanation for the poor 'findability' of the information about these themes was not found. However, a possible explanation could be that health care providers write most of the patient information and patients are usually not involved in the creation of patient information [25-27]. As a result, the information may be focused on the IUI and/or IVF/ICSI procedures, different kinds of medication and time schedule of the treatment and less on practical advice, side-effects of medication and blood loss. If this is true, a solution could be to invite patients, as the end users of the information, to participate or assist in the creation of new supply-driven patient information. This especially goes for (post) treatment patients as they have gained a wealth of experience-based knowledge. Nowadays, new collaborative technologies exist such as wikis exist that could enable patients to participate [28]. An example within an infertility care setting involving a wiki is

the recent study by Den Breejen et al. 2012 [29]. This study showed that wikis enable patients to participate by adding and rating recommendations for clinical practice guidelines. Health care providers should also realize that developing patient information leaflets is a continuous, dynamic process, which is never finished. Treatment options and patients' needs change continuously. Thus, they should explore new ways of involving patients in the creation of patient information and embrace new ways of keeping patient information up-to-date.

One in every 7th question asked by patients could be answered fully with the information from the information leaflets. It seems interesting to explore the reasons for these 'unnecessary' questions, since it could save the clinic time and effort if they would not have to give these answers. Besides, high quality information can help reducing the burden in fertility care [30]. As it is known that patients have many different sources of information including their physician, the Internet, family and friends [3], and that preferences regarding written information can be different for individual patients [31], it may be that some patients do not consult the patient information provided by the fertility clinic. One explanation could be that some patients contact their clinic for reassurance, irrespective of whether the question they have is addressed in the patient information literature. Other hypothetical explanations could be that patients: (1) do not rely on the information in the leaflets, (2) prefer an answer that fully fits their individual situation or circumstances (i.e., pre-existing medical conditions, previous obstetric or gynaecological history) or (3) that it is unclear or difficult to find the information they need (i.e., because the two leaflets used were more than 30 pages long). Regarding this last point, it should be considered that patients are often having troubles trying to recall provided (verbal) information [32]. Therefore, it is relevant for future projects to determine the extent to which infertile patients make use of the patient information leaflets that are provided by the clinic and to which extent they rely on it. This will give more insight about how many phone calls or questions on the forum can be classified as unnecessary or 'unjustified'.

Strength and limitations

The main strength of this study is that we used an innovative approach of determining gaps in the patient information provided. Furthermore, we included a combination of different sources of supply-driven information and many questions. This allowed the identification of a large diversity of themes. The level of agreement of the different reviewers was good to excellent, which contributed to the quality of our findings. Therefore, we believe that our approach shows that there are easy ways to include patients' perspectives and thus of indirect patient participation. Moreover, it can be a first step towards improvement of patient information and also towards dynamic patient information. Even so, our study does have some limitations. First, it is important to realize that the present study did not assess the overall quality of the patient information leaflet. For example, it did not include important quality criterions such as readability and layout [30], and we did not focus on the 'understandability' of information. Also, it is possible that the patient information provided contains irrelevant themes. Therefore, future research should aim at

determining the quality of patient information leaflets. Moreover, it should be evaluated how patients rate and perceive the quality of the leaflet. Second, our study only included literal questions or "manifest content" of the questions being asked. Since the manifest content can be different from "latent content", the underlying meaning of the text [21,22], it should be considered that some questions included in the present study may be different from the true patients' needs. Therefore, we recommend future studies to include the latent content if possible. Third and last, it should be realized that the present study included one fertility clinic using its own patient leaflets. Although most Dutch clinics have based their patient information leaflets on the guidelines of the Dutch Society of Obstetrics and Gynaecology, differences regarding information provision between different fertility clinics may exist [17].

Implications

Health care providers should be aware that infertile patients demand high quality information and that the information they provide does not necessarily cover all demand-driven information needs. Therefore, they should explore ways of involving patients in the creation of patient information. This will provide insight into the informational needs of patients, and will help health care providers to keep their supply-driven information up-to-date and patient-centered. Future studies should identify how this could be achieved, e.g. by new interventions or new educational materials.

Conclusion

'Listening' to patients by evaluating their questions is an easy and innovative approach of indirect patient participation, which has proven to be a feasible approach to identifying gaps in patient leaflets and to be a first step towards improving information provision.

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9

General discussion

Principal findings

This thesis is about the increased uptake of social media in health care and its rapidly growing impact. In part 1, we identified seven recurrent themes for Health 2.0 and Medicine 2.0 and concluded that the two terms can be used as synonyms. Furthermore, we demonstrated that they refer to mutual participation and empowerment of the stakeholders in health care. We used an online social network for the dissemination of a survey, and showed that nowadays' consumers in the Netherlands, regardless of their age or educational levels, rely heavily on the Internet for health-related information. Moreover, we found that one in every five Dutch consumers wants to communicate online with health care professionals, screen-to-screen. In part two of this thesis we explored the feasibility and potential impact of asynchronous online communication technologies in health care, as these can be considered to be means of engaging patients. In a scoping review, we showed that collaborative writing applications (CWAs) are used in health care, mostly by professionals, followed by scientists and patients. Furthermore, we found that CWAs (e.g. Wikis) are mainly used for academic, clinical or personal purposes. Based on the results of 111 papers, we created a taxonomy of beneficial aspects attributed to the use of CWAs in health care including; quality improvements, efficiency of communication, cost-efficiency, ease of use and that they can be used independent of time and place. However, we also found a large pallet of barriers for the use of CWA's. Our feasibility study with a Wiki in Dutch fertility care showed that patients and professionals can collaborate on improving patient information material using a CWA, but that the total number of contributions is low and that a small number of participants is responsible for the majority of contributions. In a second pilot study, we showed that online forums could be used to easily identify gaps in patient education material. In this concluding chapter, we will put our findings in perspective.

Web 2.0 and Health 2.0

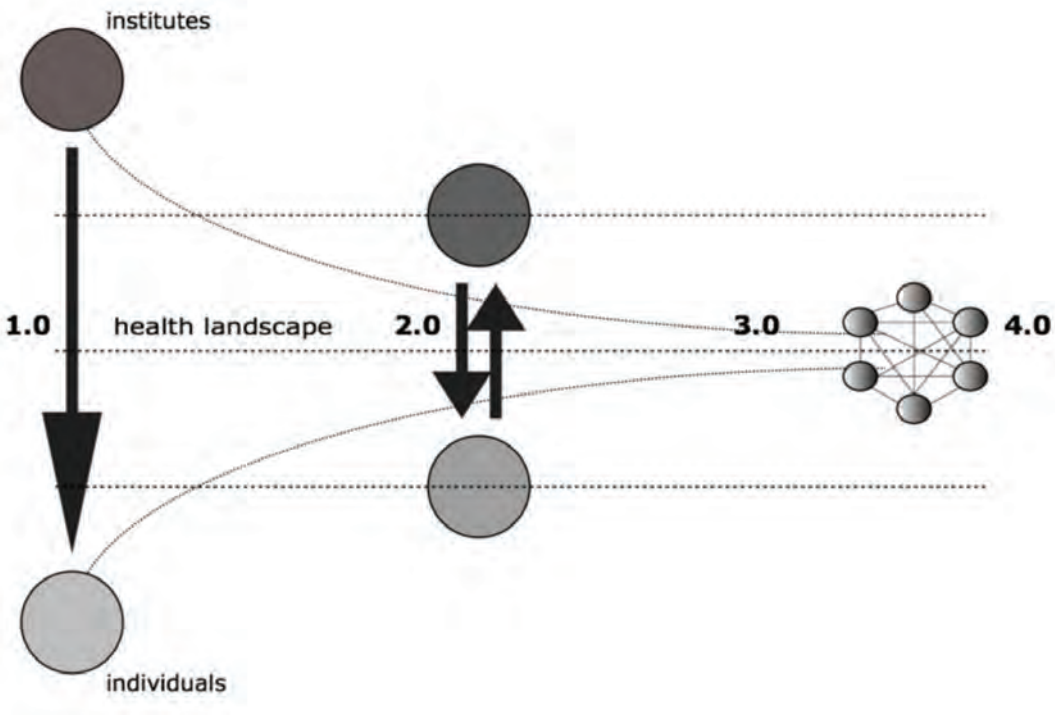
In this thesis we recognized that a Web 2.0 technologies are increasingly used in healthcare, which is called Health 2.0. (Chapter 2) The seven recurrent themes that were identified for Health 2.0 – also known as Medicine 2.0 – helped define the scope of this new field. Although definitions overlapped, the fact that we found 46 unique definitions clearly shows that there is no general consensus of the definition of Health 2.0. If social media and the six other topics that were identified are combined in one definition, a comprehensive definition for Health 2.0 emerges:

> *"A constantly evolving state of health care in which stakeholders in health care (patients, professionals, researchers, students) effectively collaborate and stimulate participatory health care by using social media and other Web 2.0 technologies."*

This comprehensive definition includes the main stakeholders of healthcare and it mentions social media separately, since it is important for Health 2.0 applications [1]. It also emphasizes the participatory nature of Health 2.0 which is, in our opinion, is relevant to include in the definition

since all stakeholders are given the same power (enabled by Web 2.0 technologies) to access the same information. It is seen as an important driving force for new initiatives in patient-centered care, reduction of cost, and research [2]. Particularly for patients, it means that they can become actively involved in their own treatment [3]. For example, patients can now directly access sources of medical information [4], which was more difficult before the Web 2.0 era (which started around 2000) and nearly impossible before the Internet era (which started around 1990). This enables patients to participate and to become more equal partners. Although patients have been described as "experts of their own disease" in the past [5], we believe that Web 2.0 technologies boost this process. Furthermore, other stakeholders such as health care professionals or researchers can also be empowered since they can learn more about patients by connecting with patients outside the clinical encounter, for example via patients' online communities. Following the idea presented by Dijkgraaf (2013) in his TEDxRadboudU-talk [6], who stated that boundaries between scientists and the rest of our society are becoming vague since everybody is critical and wants to find out how things work, we recognize a similar process in healthcare due to Web 2.0. This process has been also been recognized by Engelen and Derksen (2010) [7]. Their model (Figure 1) demonstrates how, through the use of interactive Web 2.0 tools, the gap between "institutes" (e.g. healthcare providers or hospitals) and patients is bridged.

Figure 1. Stakeholders move closer and boundaries could become vague in the future



Source: Engelen and Derksen (2010) [7].

A manifestation is patients obtaining relevant knowledge and skills that were previously reserved for healthcare professionals only and vice versa; in other words, a reduction in information

asymmetry. For the future, they predict that all stakeholders in health care will use the same sources of information, shared via online networks. This last phase (3.0 and 4.0) has been described as "swimming in a common pond of information" [8].

Health 2.0 and e-Health

Given the definition of Health 2.0, there is at least a relation between e-Health and Health 2.0, if not overlap. Although no systematic review has been performed in order to come to a comprehensive definition of e-Health, papers have attempted to define it [9]. E-Health definitions that are often referred to are the definitions of Eysenbach and Eng [10].

> *"e-Health is the use of emerging information and communications technology, especially the Internet, to improve or enable health and health care" [11].*

> *"e-Health is an emerging field of medical informatics, referring to the organization and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology" [12].*

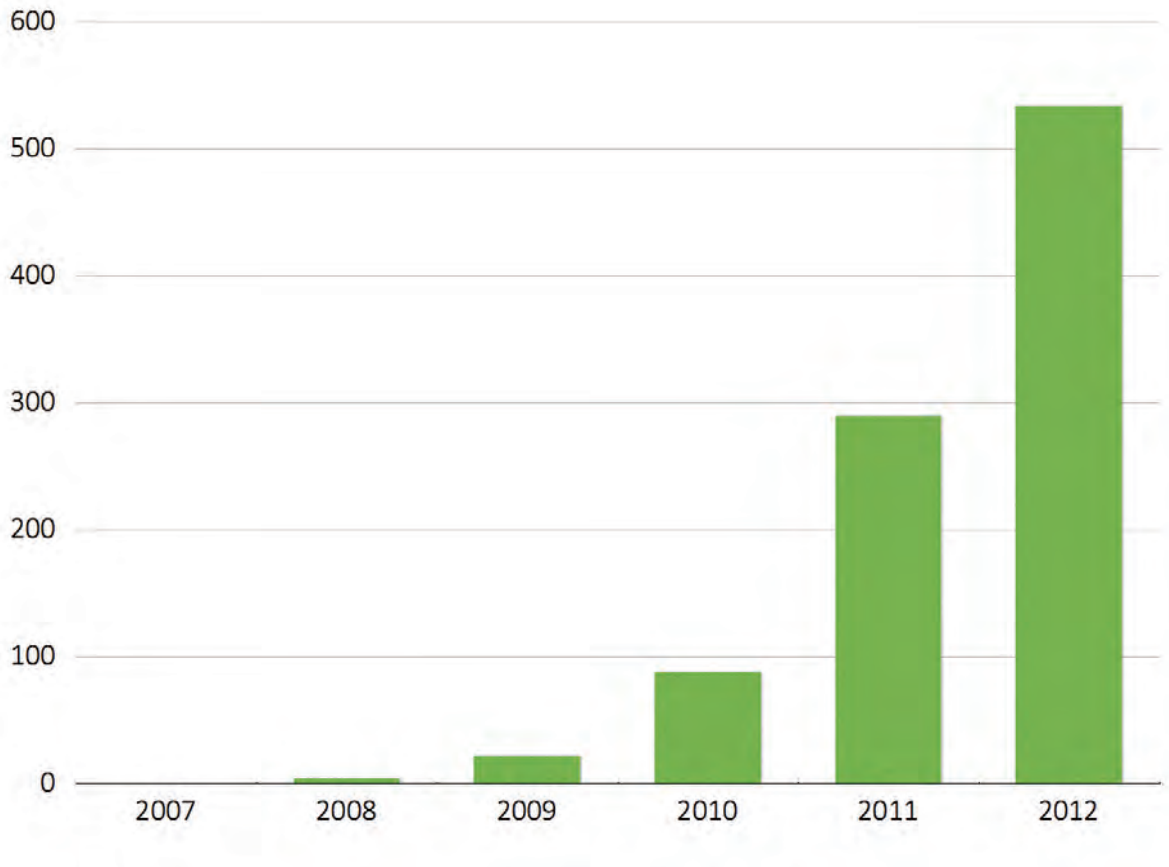
When critically comparing the two definitions to the one we proposed for Health 2.0, it becomes clear that there is a lot of overlap since both are related to technology, health informatics, Internet and healthcare. Eysenbach's definition also includes a broader sense with a new way of working, which is also included in the definition of Health 2.0. However, Health 2.0 distinguishes itself from e-Health for several reasons. First, Health 2.0 describes a continuously evolving process instead of a snapshot only. Second, Health 2.0 includes social media and collaboration with multiple stakeholders, which makes it relevant for all stakeholders in healthcare including patients, professionals and researchers. Third, it is possible to pursue Health 2.0 without technology (Chapter 2). For example, a patient can actively contribute and collaborate with a healthcare professional (if this professional supports or encourages this), by learning about his disease and treatment options through going to the library. This is not the case for e-Health, which cannot exist without technology. Consequently, we recognize that Health 2.0 is more like an 'umbrella term', that includes other terms like e-Health.

Social media

We showed that social media are an important key element of Health 2.0 and that they affect all stakeholders in healthcare e.g. by empowering them or by supporting collaboration. Furthermore, social media are 'booming' in the scientific world. Figure 2 shows that the number of publications on social media has grown rapidly (the number of papers almost doubled every year), from zero in

2007 to over 500 in 2012. Therefore, we decided to focus on social media in this discussion. Several aspects of social media will be discussed.

Figure 2. Published papers (n) about social media in PubMed*



* Search string: "Social Media" [All fields].

Benefits of social media

In this thesis we showed how social media could affect healthcare in a positive way. In particular, we focused on CWAs and created a comprehensive taxonomy of perceived beneficial aspects found in 111 studies (Chapter 6). We concluded that CWAs positively affect processes (or intermediate outcomes) and outcomes of healthcare. Processes were found to consist of: (1) Psychological domains e.g. engagement, self-efficacy, patient participation (2) Learning effects e.g. improved knowledge of students or professionals, (3) Communication e.g. improved communication between patients and healthcare professionals, (4) Collaboration e.g. improved collaboration by stakeholders and (5) Knowledge management e.g. better dissemination of information. Outcomes were found to consist of: (1) Efficiency e.g. time saving, (2) Quality e.g. better quality of patient information and (3) Disease prevention e.g. tobacco cessation skills. Our findings almost seamlessly integrate with results from other studies focused on social media for health care. In recent years, the number of publications about social media in relation to health care increased rapidly, including scoping reviews [13] and systematic reviews [14-16]. Based on

the results of a systematic review including 98 papers, Moorhead et al. (2013) defined six groups of beneficial aspects of social media for health communication: (1) Increased interaction, (2) More available, shared and tailored information, (3) Accessibility and widening access, (4) Peer/social/emotional support, (5) Public health surveillance and (6) Potential to influence health policy [16]. Interestingly, it was found that all six aspects affected the consumers, patients and health care professionals. Other studies confirmed that social media can affect patients' health outcomes (e.g. blood glucose levels, and dietary water intake) and that it engages patients [17] and improves their self-efficacy [15]. We found similar results in our scoping review about CWAs (Chapter 6). In the field of medical education, social media's communication features could improve clinical education [14]. Other interesting findings are that social media could be able to engage populations that are hard to reach like adolescents and ethnic minorities [18]. Regarding the number of papers that describe beneficial aspects of social media, it seems clear that social media can affect healthcare in a positive way and therefore, that it is a must for all stakeholders in health care to take advantage of social media and to explore how they can use it professionally (health care providers and researchers) or for their personal situation (patients). However, cautiousness is advised since, at the present time, the level of evidence of the published studies generally is low. This point will be discussed later in this chapter.

Adverse effects of social media

We showed that some adverse or potentially harmful effects of social media have been described in the literature (Chapter 6). Although the number of studies reporting adverse effects was low (possibly due to publication bias), it is important to discuss them carefully, to allow stakeholders or implementers of social media applications to anticipate on negative effects effectively. We found that the main adverse effect for CWAs is (fast) dissemination of poorly validated information. Other studies confirmed that misinformation could be a problem, and that this also applies to other types of social media [13,16]. For patients it can be particularly difficult to determine which information is reliable, which has been recognized as a problem for information on the Internet in general (Chapters 3, 4, 7) [19]. For professionals, it is impossible to control or assure the quality of online content. As a result, patient's health could be in jeopardy (Chapter 6). Other adverse effects that have been described in the literature are privacy issues e.g. difficult for users to decide whether information is shared or not, and negative outcomes due to peer pressure [13]. Another hypothetical adverse effect related to privacy is that stakeholders that share data online via social media can never be sure what is done with their information. For example, countless health-related apps are available for smartphones [20]. Many are freely available and have functionalities to map anthropometrics like weight, blood pressure, and glucose levels. They are very useful for the user, but it could also be very interesting for companies to sell or buy data of many users. Although we did not investigate this, we know that companies sell their data. An example of such a company is the large US-based online patient community PatientsLikeMe, that invites anyone to pay for access to their data [21].

Use of social media and stakeholders' preferences

Our observation that social media are increasingly being used in healthcare (e.g. hospitals that use LinkedIn for recruitment of personnel or the use of Facebook and Twitter to disseminate information) (Chapter 3, 6) corresponds to the trend that is generally recognized in Western societies [22]. The key question is whether the social media that have become mainstream in our society (Chapter 1) have also become mainstream in health care. Although we found many examples of social media applications and interventions in the different studies undertaken for this thesis, we believe social media are not yet mainstream in (Dutch) health care. Our observation was that many 'simple' things are still impossible. For example, it is not possible to make an appointment with a doctor or hospital via social media, and there are only a few examples of health care organizations in the Netherlands that allow patients to ask questions via social media [23, 24]. This also goes for other Web 2.0 technologies. For example, most patient still do not have access to online personal health records [25].

In Chapter 4, we described that the majority of consumers use the Internet for healthcare related purposes (e.g. to obtain health-related information). Interestingly, we also presented that 1 in every 4 consumers in the Netherlands wants to use social media to communicate with their healthcare provider (Chapter 4) and we argued that this group would grow rapidly. This has been confirmed by a recent study by Tackeray et al. (2013), which was focused on online search behavior and use of social media for healthcare-related purposes [26]. The results show that young adults were one of the groups that were most likely to use social media to obtain health-related information. In Chapter 7, we showed that infertile patients favored the idea to use social media (Wikis) to enable participation and collaboration with peers and health care providers.

Social Media: Yes or No?

It may be clear that social media are promising tools that have the potential to affect health care in a positive way. Although several negative effects have been described, and a lot is still unknown (e.g. about its impact), we advise all stakeholders in healthcare to get acquainted with social media. This is the only way to find out if they can benefit from it or not. Getting familiar with social media is especially important for health care organizations and providers, since a growing number of consumers and patients prefer to use social media for healthcare-related purposes. In our opinion, it is a missed opportunity that health care does not meet consumers' and patients' wishes and we observe a huge gap between "what is possible with social media", and "what is actually being done with social media". A metaphor to describe the situation we are in regarding social media in healthcare is the situation just before the Age of Discovery (15^{th} and 16^{th} century). At that time, the world map looked very different (e.g. from the perspective of Europeans, North America did not exist), as shown in Figure 3. Many questions existed about 'unknown places' that still had to be discovered. The Europeans were curious, and believed that they could benefit from discovering new land (e.g. for resources, trading). Although they were not sure about the benefits and had no clue what they would find, they realized that the only solution was to start exploring.

They needed courageous men, and sponsors that had the guts to pay for the expensive trips. More importantly, they needed patience. It could take years to discover what the world map looked like and how they could benefit best from the newly discovered places.

Figure 3. World map of the year 1502

(Source: Wikipedia [http://en.wikipedia.org/wiki/File:Cantino_planisphere_(1502).jpg])

Challenges

When starting to explore social media for health care (e.g. by implementing a social media tool and studying its effects), some important challenges exist. These challenges may explain the slow uptake of social media in health care. To overcome these challenges, we will discuss them in depth and deliberate on possible solutions to deal with the challenges.

Challenge 1: Evidence

The first and probably most important challenge is to find sufficient evidence that social media are effective and that there is sufficient insight into potential adverse effects for patients or professionals. Since the healthcare sector, especially medicine, will only embrace new technology if satisfactory evidence is available, the uptake of social media remains low. Therefore, there is a strong need for evidence. Although we have seen the number of published papers investigating social media for health care growing rapidly over the past few years, we showed that most studies about collaborative writing applications had observational and explorative designs (Chapter 6). This was also found in other studies [14,15]. A systematic review performed by Moorhead et al. (2013) concluded that more robust methodology and larger sample sizes are needed [16]. The authors also identified eight main gaps in the literature which have been insufficiently addressed: (1) The suitability of social media for different populations, (2) Relative effectiveness of different applications, (3) Long-term effectiveness, (4) Insight in mechanisms to monitor the effectiveness,

(5) Insight in the risks of sharing information online, (6) Full potential of social media in effectively supporting the patient-professional relationship, (7) Impact of social media peer-to-peer support for stakeholders to enhance interpersonal communication, and (8) Impact of social media on behavior change.

In our attempt to obtain the so needed evidence, we proposed that studies with longitudinal or experimental designs would be helpful (Chapter 6), especially Randomized Controlled Trials (RCTs). They are, despite some critics [27], generally seen as the golden standard for biomedical research [28,29]. However, social media interventions are difficult to evaluate using experimental designs like RCTs, because of the complexity of the interventions and causal chains [29]. Moreover, it is difficult to standardize and control for all factors that influence social media interventions, since the intervention and its context (e.g. users and organization) are 'alive', which means that they can change during the research period [30-32]. For example, when performing an experiment involving a social media network for patients and their caregivers, researchers should realize that (1) the intervention's features are likely to change due to new insights e.g. newly installed chat module, safety updates or bug fixes and (2) patients and professionals may be influenced by many other social media networks e.g. if they find better alternatives online. It is impossible to control for all variables and unrealistic sample sizes may be required to measure any effect. Therefore, innovative study designs are needed [15]. Several researchers have acknowledged the challenges with the development, evaluation and implementation of complex interventions. They recommend to use qualitative or mixed method approaches (i.e. a combination of quantitative and qualitative methodologies) to study complex interventions [30, 33], especially since qualitative methods are helpful to study new, unusual or rare occasions [34]. We agree, especially since social media allow stakeholders (e.g. patients) to 'personalize' their care, many differences between individuals may appear and therefore it may be relevant to focus on unusual or rare preferences or occasions. The Medical Research Council (MRC) has described more vigorous guidance during the stages of designing and evaluating complex interventions [32]. Therefore, their framework could be important for social media interventions. It emphasizes that sufficient pilot and feasibility studies should be performed, to prevent future RCT's from failing. In Chapter 7, we have successfully done this for two wikis. The results of this study, along with barriers and facilitators that we described in Chapter 6, could be helpful for future implementers of CWAs in health care.

Challenge 2: Addressing barriers

The second challenge is to address the barriers that hinder successful use or uptake of social media. In this thesis, we showed that many barriers for the use of CWAs in health care exist, of which "worries about the scientific quality" was the most recurrent one (Chapter 6, 7). Another study investigating patients' interest in social media for health care found that, according to patients, privacy and confidentiality was the most important barrier, followed by lack of personal benefit and high costs [35]. Furthermore, we witnessed that most studies involving CWAs did not identify potential barriers nor discussed ways to address them. Moreover, it seems that most

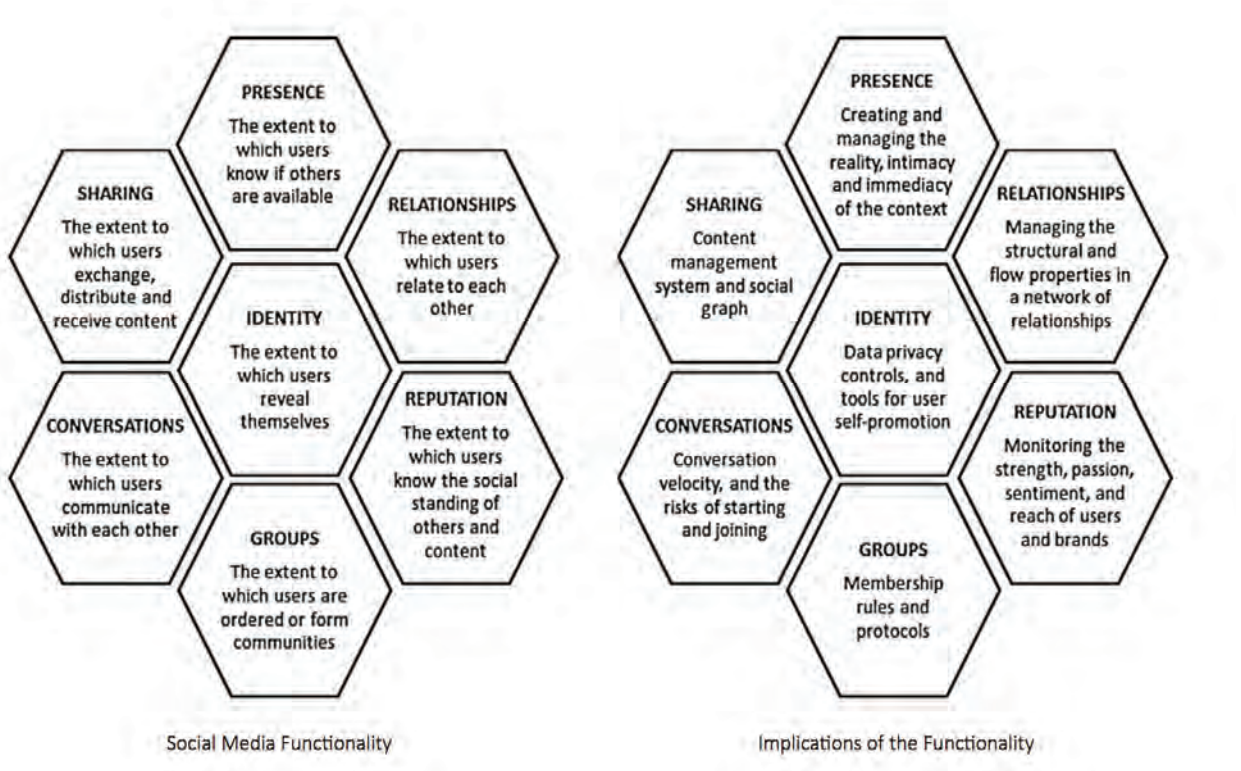
social media applications are developed without perceiving potential adverse effects. As a result, unexpected barriers and negative effects can show up. Since we know from implementation literature that new applications do not implement themselves [36,37] and that it is important to gain insight into the barriers and negative effects that can be expected, we developed a comprehensive taxonomy of relevant barriers for the use of collaborative writing applications in health care. The taxonomy was developed based on existing frameworks, which were further improved based on our studies' findings. It can guide future researchers and implementers of social media, particularly CWAs such as wikis.

Regarding the diversity of social media and potential applications, and the many potential barriers, we believe that guidance by for example frameworks could be useful for researchers and implementers to optimize the chances of successful development and implementation of social media. Since we discovered that there is overlap between e-Health and Health 2.0 (Chapter 2), future researchers and implementers of social media could probably benefit from frameworks for development, evaluation and implementation of e-Health interventions [30,33,38]. An e-Health framework that could meet the requirements for social media is the STAR-model described by Chou et al. (2013) [15], which consists of five logical steps: (1) Identifying users' needs, (2) Planning ways that technology can meet these needs, (3) Implementing these plans in system design, (4) Reviewing the system and adjusting the design based on user feedback and, (5) Implementing the system. If implementers follow this approach for the development of social media tools, barriers are probably recognized in an early phase, since the end users are involved from the beginning. In Chapter 7, we involved patients from the beginning, and invited them to co-create two wikis. Although we found that this approach helped us to anticipate on potential barriers effectively we found that it was impossible to anticipate every barrier from the beginning. This was caused by unexpected events consisting of functionality changes due to software updates. We foresee that this will continue to happen in the future and we propose that regarding social media interventions, implementation is never over and it should be a continuous and iterative process. Concerning the STAR framework, this would mean that step four and five would be repeated continuously.

Although not related to healthcare, frameworks developed specifically for social media exist. They can be of interest for implementers of social media applications in healthcare, since they include social media specific aspects. Kietzmann et al. (2011), proposed "The Honeycomb Framework", which was created to support businesses in dealing with social media [39]. Figure 4 shows seven building blocks of social media features (and their implications) including identity, presence, relationships, reputation, groups, conversations and sharing. For example, the building block "identity" is described as "the extent to which users reveal themselves" and the implication is described as "data privacy controls and tools for user self-promotion". Making use of this framework, users see the difference between social media tools, e.g. regarding their functionalities and their impact. This could be relevant for health care as it gives insight in the

different features of social media and the barriers that can be expected. For example, if this framework were used for the online social network for infertile patients as described in Chapter 7, it would become clear that the first building block "identity" would show that barriers regarding privacy and confidentiality may be expected, and chat safety is important (infertility is a serious medical condition so protecting the patient's privacy is important, especially since infertility has been surrounded by taboos for a long time). Moreover, additional usability barriers should be expected because securing data often results in complicated login procedures (Chapter 7).

Figure 4. The Honeycomb Framework



Source: Kietzmann et al. (2011)) [39].

Challenge 3: Change

The third challenge comprehends change, which is needed to implement or to study social media in health care successfully and eventually to let health care benefit from social media. Researchers and implementers should consider that health care is often regarded as a conservative system, which is not very keen on embracing new technologies (other than medical technology) e.g. social media. Although a trend from a paternalistic system ("the doctor knows what the patient needs") to a more pluralistic or "patient centered" system is witnessed [40], we believe that there is still a long way to go until health care organizations and providers will be more open to social media. As described in Chapter 1, there is still a remarkable difference between health care and other sectors like the commercial sector, in which the opinion of the customer directly affects business models. Moreover, it seems that health care professionals do not yet realize that social media already is affecting health care and that patients are having conversations about them within

social media channels [39]. Furthermore, it is known that, with the exception of medical technology, the uptake of technology in health care can lag behind compared to other sectors, like the business sector. An example is the adoption of Internet and Communication Technologies (ICTs) by healthcare providers, which can be as much as 25 to 30 years behind [41]. This could also go for social media. To achieve that healthcare is more open to social media, a first recommendation is to educate health care professionals about social media and all of its features. We believe that this will make 'the unknown known' and could reduce hesitation, resistance and even anxiety among professionals. Fortunately, the first initiatives to educate professionals have already appeared. Dr. Bertalan Mesko, a health care professional and researcher from Hungary, realized that social media are changing medicine and that medical education needs to be updated. He developed an online social media course specifically for medical students [42], in which they learn how to use social media safely and effectively (for personal and professional purposes). It consists of 16 topics e.g. Wikipedia, microblogging and YouTube. Furthermore, the Mayo Clinics in the USA and the Radboud University Medical Center in the Netherlands realized that healthcare could benefit from social media. They created an international social media network with the primary goal to educate its members how to implement social media in health care. They do this by organizing (online) meetings and by sharing experiences, training materials and other resources. A second recommendation, that seems relevant for implementers of social media tools, is to change health care (and eventually the paradigm) by taking very small steps. This was first addressed by American psychologist BJ Fogg (2012) who describes, that people can only change their behavior in a structural way if they take very small (and thus easy) steps [43]. If the steps are too big, too much motivation is needed to change behavior and it is impossible to maintain new behavior for a longer period of time. As a result, a structural change of behavior is impossible. For example, inviting a health care professional to answer patients' questions via Twitter once a day, is more likely to succeed than inviting this professional to answer questions via different types of social media.

Challenge 4: Dealing with financial issues

A fourth and last challenge is dealing with financial issues. In Chapter 7, we showed that financial issues can hinder the use and implementation of social media. Also, it is known that health care organizations will only embrace innovations if they are convinced that they will benefit from it. This is an interesting paradox: On the one hand healthcare organizations will only invest in social media if they are convinced about the benefits, but to make the benefits visible, sufficient funding is needed for careful development, pilot testing and implementation. Such a paradox has also been recognized in the past for the implementation of ICTs [44]. Next to performing more pilot studies (which are less expensive), we believe that new business models may be needed to support the development of innovative tools such as social media. An example of an innovative way of funding is "Crowdfunding", which means that projects are sponsored by many individuals. A Dutch example of such a project is "MedCrowdFund", a website that allows anyone (including

patients and their peers) to co-create research plans and fund (research) projects that they feel are relevant for healthcare by sharing through social media. [45].

Clinical relevance

We believe that our findings are relevant for all stakeholders in health care, particularly for patients, health care providers and researchers. It is clear that any stakeholder in health care will have to deal with social media, whether or not they want to. Patients may realize that they have access to tools that they did not have in the past. They can access the same information as health care professionals and can always find support from patients with similar conditions. Furthermore, we believe that patients could realize that they now have the opportunity to become more equal partners of health care providers and that they have the tools to personalize health care. Engelen (2010) described how patients could do this [46]. Before they start using social media for healthcare-related purposes, they should take into account the risks of sharing personal health data online. An example of a patient that really has become a partner of the professional is e-Patient Dave [47]. He survived a rare malignant tumor by making use of social media. The social media allowed him to learn about his disease (he became an expert of his own disease), find other patients that had a similar tumor and also how he could be treated. Even his own doctors were not aware of this treatment [48].

Health care providers should explore the different ways they can benefit from social media. They not only have the tools to quickly find or share relevant medical information, but also have new opportunities to efficiently communicate or collaborate with patients, listen to their feelings and experiences and more importantly, they can better support them which can affect health outcomes in a positive way. Our project in which health care providers and patients collaboratively worked on a patient information leaflet (Chapter 7) showed that both providers and patients favored this new approach. Since social media have affected the field of learning, health care providers (especially educators) should explore the different opportunities for medical education. For them, it is important to understand the risks of being active on social media. For that, the Royal Dutch Society of Medicine (KNMG) has published a document with Social Media guidelines for health care professionals [49].

Researchers should realize that they could easily participate in large collaborative projects, not hindered by place and time limitations [50,51]. Furthermore, it is clear that research can benefit from social networks e.g. patient or professional networks. They offer a plethora of relevant information, facilitate easy recruitment of subjects [52] and quick dissemination of surveys. Furthermore, researchers can use social media to efficiently collect data, as they can now "crowd source" data [53]. For example, patients' communities offer information relevant for researchers [54]. Another example is AED4.EU, a website where data about Automatic External Defibrillators is collected and can be uploaded by any Internet user [55]. This allows researchers to quickly gather huge amounts of data that can be analyzed directly. A final reason why researchers should be

open to social media is that social can also be used to predict the quality of health care [56] and even the impact of scientific publications [57].

Future perspectives

Health care is facing challenges. People grow older, more people have chronic diseases and we are able to cure many rare diseases. As a result, healthcare is becoming more expensive every year. A possible solution to deal with the challenges can be technology [58]. We believe that social media, if carefully implemented, may help to deal with these challenges. Furthermore, it should be realized that patients would become further empowered in the upcoming years. Future generations will increasingly use social media for healthcare-related purposes and it is up to health care organizations, professionals and researcher to adapt to it [59].

Final conclusions

Social media are promising tools that will further affect health care in the upcoming years, as they do to our whole society. Yet, the precise direction, speed and magnitude are unknown. Health care organizations, professionals, patients and researchers should explore if and how they can benefit from social media. This thesis helped identifying the scope and terminology for this new "Health care Social Media era". Moreover, it provided insight into the feasibility of using social media in health care, and the opportunities and challenges that exist.

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Summary

Chapter 1

This chapter contains the general introduction of the thesis and describes the background and rationale of the studies performed. The focus of this thesis is on the use of the Internet and particularly social media in health care. The Internet has become an interactive medium, also known as 'Web 2.0', and the Internet and social media increasingly influence our society by empowering users. The collaborative nature of Web 2.0 could influence health care in a positive way, for example by improving communication between stakeholders and efficient knowledge dissemination. Based on several examples of how different stakeholders already use the Internet and social media for health care-related purposes, we concluded that the Internet and especially social media have the potential to affect health care and that they will increasingly influence health care in the future. Although positive effects like quality improvements are to be expected, several questions remain unanswered, for example about the terminology, feasibility, safety and privacy issues. This thesis aims to provide an answer to some of those questions by giving insight in the different terminology, the different types of social media that are used, and how this develops over time. Moreover, it provides insight into the feasibility of using social media in health care, and the opportunities and challenges that exist. We therefore consider this thesis as a critical step in the development of this new research field. This thesis is divided into two parts. Part one focuses on social media and health care in general. Part two concentrates on two specific examples of social media: collaborative writing applications and forums, both examples of asynchronous communication. We defined the following research questions:

Part 1:

1. Is it possible to define Health 2.0 and Medicine 2.0? (Chapter 2)
2. To which extent are social media being used in health care? (Chapter 3)
3. In which way does the general population use the Internet and social media to find health-related information and what are the preferences of the general population regarding online communication with health care providers? (Chapter 4)

Part 2:

4. What are online collaborative writing applications and what are positive and negative effects, and barriers and facilitators of using online collaborative writing applications in health care? (Chapter 5 and 6)
5. To which extent is the use of collaborative writing applications feasible to stimulate patient participation and collaboration with health care providers? (Chapter 7)
6. How can online forums be used to improve patient information? (Chapter 8)

Part one: Health care and Social Media in general

Chapter 2

The term Web 2.0 is increasingly applied in health care and can be recognized as "Health 2.0" or "Medicine 2.0". Although a clear definition is important for both the development of new Health 2.0 initiatives and the comparability of new research developments, little is known about this concept and discussion about the definition continues. Therefore, we performed a systematic review to identify unique definitions of Health 2.0 and recurrent topics within the definitions. We searched both scientific databases and gray literature (using Google, Bing, and Yahoo). A total of 1937 articles were screened and 46 unique definitions were identified. Using the constant comparison method, we identified seven main topics for Health 2.0; patients, Web 2.0/technology, professionals, social networking, change of health care, collaboration, and health information/content. We concluded that, despite the large number of papers that were found, there is no general consensus regarding the definition of Health 2.0 and the field is still developing. The seven topics identified contribute to further building the concept of Health 2.0.

Chapter 3

Active use of social media by health care institutions could speed up communication and information provision to patients and their families and consequently increase quality of care. Hospitals seem to be becoming aware of the benefits social media could offer. Data show that hospitals in the United States increasingly use social media, but for Western European hospitals this is still unknown. Therefore, the study presented in this chapter, aimed at identifying to what extent hospitals use social media, by conducting a longitudinal study including 873 hospitals from 12 Western European countries. We collected data for each country during the following three time periods: April to August 2009, August to December 2010, and April to July 2011. The use of social media increased significantly over time, especially for YouTube (2% to 19.7%), LinkedIn (20.5% to 31.8%), and Facebook (10% to 67%). Furthermore, significant differences in social media usage between the included countries were found. Except for the Netherlands and the United Kingdom, the group of hospitals that is using social media remains small. However, usage of LinkedIn for job recruitment shows the awareness of the potential of social media. We concluded that future research is needed to investigate how social media may be used to improve health care.

Chapter 4

This chapter describes the results of a cross-sectional survey to identify how the Dutch general population locates health-related information and to determine preferences regarding the use of social media and other communication technologies in health care. This was important, since the implementation of Internet interventions (including Web 2.0 technologies) is often unsuccessful and the attrition rates are high. The survey was disseminated via a popular Dutch social network 'Hyves' and respondents were asked where they searched for health-related information, and how

they qualified the value of different sources. Moreover, we asked for their preferences regarding online communication with health care providers. Results from the 635 respondents were extrapolated to the Dutch population which showed that the Internet was the most important source of health-related information (82.7%), closely followed by information provided by health care professionals (71.1%). About one third (32.3%) of the Dutch population searched for ratings of health care providers. The most popular information topics were side effects of medication (62.5%) and symptoms (59.7%). One fourth (25.4%) of the Dutch population preferred to communicate with a health care provider via social media and 21.2% would like to communicate via a webcam. We concluded that it is important for health care providers to explore new ways of online communication and to facilitate patients in connecting with them. Future research should therefore aim at comparing different patient groups and diseases, describing best practices and determining the cost-effectiveness of the use of social media in health care.

Part 2: Asynchronous communication

Chapter 5

This chapter contains a study protocol for a scoping review involving Collaborative Writing Applications (CWAs), which are online tools that enable joint and simultaneous editing of online documents by many end-users. Probably the best example of a CWA is the online encyclopedia Wikipedia. We observed that CWAs are increasingly used in health care. Therefore, a systematic synthesis of the impact of CWAs as 'knowledge-translation-tools' (KT tools) in health care and an inventory of the factors that affect their use was needed. The overarching goal of this study was to explore the depth and breadth of evidence for the use of collaborative writing applications in health care. The purposes of this scoping review were to (1) map the literature on collaborative writing applications; (2) compare the applications' features; (3) describe the evidence of each application’s positive and negative effects as a knowledge translation intervention in health care; (4) inventory and describe the barriers and facilitators that affect the applications' use; and (5) produce an action plan and an agenda for future research. Recognized scoping review methodology was used, which consisted of six steps: (1) identifying the research question; (2) identifying relevant studies within the selected databases (using the EPPI-Reviewer software to classify the studies); (3) selecting studies (an iterative process in which two reviewers search the literature, refine the search strategy, and review articles for inclusion); (4) charting the data; (5) collating, summarizing, and reporting the results (performing a descriptive, numerical, and interpretive synthesis); and (6) consulting knowledge users during three planned meetings. The latter was a unique feature and comprehended that three national and international institutional knowledge users partnered in this research process from the beginning; the International Medical Informatics Association, the Association of Faculties of Medicine of Canada and the Federation of Patients and Consumer Organization in the Netherlands (NPCF). The results of this scoping review are described in Chapter 6.

Chapter 6

In this chapter we described the results of a scoping review to investigate the depth and breadth of evidence about the effective, safe and ethical use of Collaborative Writing Applications (CWAs) in health care. The methodology presented in Chapter 5 was used. We searched seven scientific databases and six grey literature sources for articles on CWAs published between 2001 and September 2011. 6,357 citations were screened. Studies presenting qualitative or quantitative empirical evidence concerning health care and CWAs were included. Of the 111 studies included, four were experimental, five quasi-experimental, five observational, 52 case studies, 23 surveys about wiki use and 22 descriptive studies about information quality in wikis. In 58% of the surveys conducted with health professionals and students, a high prevalence of CWA use (i.e., more than 50%) was reported. Contribution rates remain low and the quality of information in CWAs needs improvement. We identified 48 barriers, 91 facilitators, 57 positive effects and 23 negative effects. Experimental studies show that CWAs used as knowledge translation tools (KT tools) improve: physical activity, blood pressure control, scientific writing, communication and leadership. We concluded that CWAs present many potential positive and negative effects as KT tools in health care. However, before any recommendations about the effectiveness of CWA use can be made, a systematic review is needed to further synthesize the results of experimental and quasi-experimental studies, assess the risk of bias and the presence of publication bias. Furthermore, implementation strategies are needed to address barriers to their use.

Chapter 7

This chapter presents the results of a study to determine the technical feasibility of wikis in generating dynamic patient information leaflets with participation of patients and health care professionals. This was of importance, since patients – although they have gained a wealth of experienced based knowledge – are usually not involved in the development of patient information. We created an open wiki for Dutch infertile patients receiving intrauterine insemination (IUI) treatment and a closed wiki for patients receiving in vitro fertilization (IVF) at one Dutch university clinic. Feasibility was assessed by analyzing logging data and content; users' experiences and expectations were addressed by means of semi-structured interviews. Both patients and professionals worked on the information simultaneously, not hindered by time or location restrictions. The open IUI wiki was visited by 2,957 visitors and the closed IVF wiki by 424 visitors. Twenty-eight barriers (e.g. difficult login procedure) and 14 facilitators (e.g. reliable and high quality content) for using the wiki were identified. Wikis appeared to be promising tools to improve patient participation in the creation of patient information. Future studies should aim to increase the active use of wikis by testing strategies based on the wide spectrum of barriers and should evaluate the quality of the content produced.

Chapter 8

This chapter describes an observational study to determine the feasibility of an approach in which we systematically analyzed questions that infertile patients raised (demand-driven) to identify gaps in the provided patient information (supply-driven). We reasoned that health care providers should search for easy and innovative ways to keep their provided information up-to-date, since it is known that high quality information about their treatment is crucial for patients and helps patients to participate, make better decisions and may even result in improved health outcomes. This is particularly important in fertility care, as incomplete and conflicting information is a problem experienced by infertile patients. We tested the feasibility of our approach by (1) identifying themes that patients asked questions about (including an online forum) and by (2) determining to which extent the questions asked by patients could not be answered using the information leaflets provided by a fertility clinic. This allowed us to identify gaps in supply-driven patient information. A total of 193 questions were included and 24 different themes were identified (e.g. blood loss during treatment, side-effects of medication and use of medication). Interestingly, half of the patients' questions could not or only partially be answered using the conventional patient information leaflets (49.4%). The approach used is a feasible way of identifying areas of improvement and can be a first step towards improvement of supply-driven information provision. Health care providers should realize that infertile patients demand high quality information and that the information provided does not cover all demand-driven information needs. Therefore, health care providers should further explore ways of involving patients in the creation of patient information. This will provide insight into the informational needs of patients, and will help health care providers to keep their supply-driven information up-to-date and patient-centered.

Chapter 9

This chapter contains the general discussion of the research presented in this thesis. We propose a comprehensive definition of Health 2.0, which is based on the seven topics identified in Chapter 2. Since Health 2.0 facilitates patients to participate and become more equal partners, the boundaries between different stakeholders (e.g. patients and professionals) could become vague in the Health 2.0 era. When comparing Health 2.0 to other terminology, it appears that there is a lot of overlap between Health 2.0 and e-Health since both are related to technology, health informatics, Internet and health care. However, Health 2.0 distinguishes itself from e-Health for several reasons. First, Health 2.0 describes a continuously evolving process instead of a snapshot only. Second, Health 2.0 includes social media and collaboration with multiple stakeholders, which makes it relevant for all stakeholders in health care including patients, professionals and researchers. Third, it is possible to pursue Health 2.0 without technology. Thus, Health 2.0 is more like an 'umbrella term', that includes other terms like e-Health. Although social media affect health care in a positive way, cautiousness is needed since the level of evidence of most studies is generally low. Furthermore, there are several negative or potentially harmful effects that need attention, such as quick dissemination of poorly validated information or privacy issues. Since we

found that a growing number of consumers wishes to use social media for health care-related purposes, we argue that it is a missed opportunity that health care does not yet meet consumers' and patients' wishes. There still is a huge gap between "what is possible with social media" and "what is actually being done with social media". Therefore, we advise all stakeholders to explore social media and find out if and how they can benefit most. To support further development and implementation of social media in health care, four important challenges need further attention: (1) How to provide evidence that social media are effective, (2) How to address barriers for using social media, (3) How to achieve that health care is more open to social media, and (4) How to deal with financial issues. Finally, social media are promising, and will further affect health care in the upcoming years, as they do to our whole society. Yet, the precise direction, speed and magnitude are unknown. This thesis helped identifying the scope and terminology for this new "Health care Social Media era". Moreover, it provided insight into the feasibility of using social media in health care, and the opportunities and challenges that exist.

Samenvatting

Hoofdstuk 1

Dit hoofdstuk bevat de inleiding van het proefschrift en beschrijft de achtergrond en de drijfveren achter de uitgevoerde onderzoeken. De focus van dit proefschrift ligt op het gebruik van het internet en met name sociale media in de zorg. Het internet is in de loop der tijd uitgegroeid tot een interactief medium – ook bekend als "Web 2.0" – dat een steeds grotere rol speelt in het dagelijks leven. De collaboratieve aard van Web 2.0 kan mogelijk een positieve bijdrage leveren aan de zorg, bijvoorbeeld door het verbeteren van de communicatie tussen *stakeholders* of het efficiënter delen van informatie. We laten zien hoe reeds gebruik gemaakt wordt van internet en sociale media in de zorg, en concluderen dat internet en met name sociale media de potentie hebben zorg te beïnvloeden en dit waarschijnlijk in toenemende mate zullen gaan doen. Hoewel verschillende positieve effecten zoals kwaliteitsverbeteringen worden verwacht, blijven sommige vragen onbeantwoord. Het gaat dan bijvoorbeeld over de terminologie in dit nieuwe veld, de haalbaarheid van innovaties en tools, en de veiligheids- en privacy-aspecten die erbij komen kijken. In dit proefschrift proberen we antwoord te geven op enkele van deze vragen door inzicht te geven in de gebruikte terminologie, de verschillende sociale media die gebruikt worden in de zorg en hoe deze zich ontwikkelen. Bovendien geeft het inzicht in de haalbaarheid van het gebruik van sociale media in de zorg en de bijbehorende mogelijkheden, knelpunten en uitdagingen. Dit proefschrift is daarom een belangrijke stap in de ontwikkeling van een nieuw onderzoeksgebied. Het is onderverdeeld in twee delen. Deel één gaat over sociale media in relatie tot zorg in het algemeen. Deel twee gaat dieper in op twee specifieke voorbeelden van sociale media, namelijk *'collaborative writing applications'* (CWA) en fora, beide voorbeelden van asynchrone online communicatie. De vragen die centraal staan zijn de volgende:

Deel 1:

1. Is het mogelijk om *"Health 2.0"* en *"Medicine 2.0"* te definiëren? (Hoofdstuk 2)
2. In hoeverre worden sociale media gebruikt in de gezondheidszorg? (Hoofdstuk 3)
3. Op welke manier gebruikt de Nederlandse bevolking internet en sociale media om gezondheidgerelateerde informatie te verkrijgen en wat zijn de *voorkeuren* ten aanzien van online communicatie met zorgverleners? (Hoofdstuk 4)

Deel 2:

4. Wat zijn positieve en negatieve effecten van CWA's en wat zijn de belemmerende en bevorderende factoren van het gebruik ervan in de gezondheidszorg? (Hoofdstuk 5 en 6)
5. In hoeverre is het haalbaar om CWA's te gebruiken om participatie van patiënten en de samenwerking met zorgverleners te stimuleren? (Hoofdstuk 7)
6. In hoeverre is het mogelijk om online fora te gebruiken om patiënteninformatie te verbeteren? (Hoofdstuk 8)

Deel één: de zorg en sociale media

Hoofdstuk 2

De term "*Web 2.0*" wordt steeds vaker gekoppeld aan de gezondheidszorg en meestal herkend als "*Health 2.0*" of "*Medicine 2.0*". Ondanks het feit dat een heldere en allesomvattende definitie belangrijk is voor de ontwikkeling van nieuwe *Health 2.0*-toepassingen en voor de vergelijkbaarheid ervan, is er nog weinig bekend over dit concept en is heerst veel discussie over de definitie. Daarom werd een systematische review uitgevoerd om zowel unieke definities van *Health 2.0* als de belangrijkste bouwstenen hiervan te verzamelen. We doorzochten zeven wetenschappelijke databases en grijze literatuur met behulp van de zoekmachines Google, Bing en Yahoo. In totaal werden 1.937 artikelen gescreend, wat resulteerde in een lijst van 46 unieke definities. Er werden zeven hoofdonderwerpen van *Health 2.0* geïdentificeerd waaronder: patiënten, Web 2.0/Technologie, sociale media, verandering van de zorg, samenwerking en gezondheidgerelateerde informatie. We concludeerden dat, ondanks het grote aantal bronnen dat werd gevonden over dit onderwerp, er duidelijk geen consensus bestaat over het onderwerp *Health 2.0*, en dat het veld volop in ontwikkeling is. De zeven bouwstenen van *Health 2.0* kunnen bijdragen aan de verdere uitwerking van het concept *Health 2.0*.

Hoofdstuk 3

Het gebruik van sociale media door zorginstellingen verbetert de communicatie en vereenvoudigt het verstrekken van informatie aan patiënten en hun naasten, en draagt zo bij aan de kwaliteit van zorg. Ziekenhuizen lijken zich steeds meer bewust te zijn van de potentiële positieve aspecten van sociale media. Onderzoek in de Verenigde Staten laat zien dat ziekenhuizen in toenemende mate sociale media gebruiken, maar voor West-Europa is dit nog onduidelijk. De studie, beschreven in dit hoofdstuk, was erop gericht in kaart te brengen in hoeverre ziekenhuizen in West-Europa gebruik maken van sociale media. Het betrof een longitudinale studie waarbij 873 ziekenhuizen uit twaalf landen werden geïncludeerd. Voor ieder land werden data verzameld in de periodes april - augustus 2009, augustus - december 2010 en april - juli 2011. Het gebruik van sociale media nam statistisch significant toe gedurende de onderzoeksperiode, in het bijzonder voor YouTube (2% tot 19,7%), LinkedIn (20,5% tot 31,8%) en Facebook (10% tot 67%). Daarnaast werden statistisch significante verschillen gevonden tussen individuele landen, wanneer gekeken werd naar het gebruik van sociale media door ziekenhuizen. Behalve in Nederland en het Verenigd Koninkrijk blijft de groep die gebruik maakt van sociale media klein. Wel laat het gebruik van LinkedIn (bijvoorbeeld voor werving van personeel) zien dat ziekenhuizen zich bewust zijn van de mogelijkheden van sociale media. We concludeerden dat toekomstige studies in kaart dienen te brengen op welke manieren sociale media ingezet kunnen worden om de zorg te verbeteren.

Hoofdstuk 4

Dit hoofdstuk beschrijft de resultaten van een dwarsdoorsnedeonderzoek (door middel van een vragenlijst), waarbij in kaart werd gebracht hoe de Nederlandse bevolking gezondheidgerelateerde informatie vindt en wat de voorkeuren zijn ten aanzien van het gebruik van internet en andere communicatietechnologieën voor zorggerelateerde zaken. Deze studie was nodig aangezien de implementatie van internetinterventies (waaronder Web 2.0-toepassingen) vaak weinig succesvol zijn en de uitval groot is. De vragenlijst werd verspreid via het sociale netwerk Hyves. De respondenten werd gevraagd waar ze gezondheidgerelateerde informatie zochten en vonden, en wat volgens hen de waarde van de verschillende bronnen was. Daarnaast brachten we in kaart wat de voorkeuren waren ten aanzien van online communicatie met zorgverleners. De resultaten van 635 respondenten werden geëxtrapoleerd naar de gehele Nederlandse bevolking. Daaruit bleek dat internet de belangrijkste bron van gezondheidgerelateerde informatie is (82,7%), op de voet gevolgd door informatie verstrekt door zorgverleners (71,1%). Ongeveer één derde (32,3%) van de Nederlandse bevolking zoekt online naar beoordelingen van zorgverleners. De meest gezochte onderwerpen zijn informatie over bijwerkingen (62,5%) en symptomen (59,7%). Eén vierde (25,4%) van de Nederlandse bevolking zou willen communiceren met een zorgverlener via sociale media en 21,2% zou dit willen doen via een webcam. We concluderen dat het voor zorgverleners belangrijk is om nieuwe manieren van (online) communicatie te verkennen, en om het voor patiënten mogelijk te maken op nieuwe manieren te communiceren. Toekomstige studies moeten gericht zijn op het vergelijken van het gebruik van sociale media ten aanzien van verschillende patiëntengroepen en/of aandoeningen, het beschrijven van succesvolle toepassingen (best practices) en het bepalen van de kosteneffectiviteit van het gebruik van sociale media in de zorg.

Deel 2: Asynchrone communicatie

Hoofdstuk 5

Hoofdstuk 5 beschrijft een studieprotocol voor een scoping review over CWA's. Dit zijn online tools die het mogelijk maken dat meerdere mensen tegelijkertijd aan online documenten werken. Het beste voorbeeld van een CWA is waarschijnlijk Wikipedia, de online encyclopedie. Aangezien CWA's in toenemende mate worden gebruikt in de zorg is het nodig om de impact ervan, met name ten aanzien van het overbrengen van kennis, systematisch in kaart te brengen. Ook dienen factoren, die het gebruik van CWA's beïnvloeden, bestudeerd te worden. Het hoofddoel van deze studie was daarom te verkennen in hoeverre CWA's op dit moment gebruikt worden in de zorg, en bewijs over de werkzaamheid ervan te verzamelen. Meer specifiek betekent dit: (1) het verzamelen van literatuur over CWA's, (2) het vergelijken van de kenmerken van verschillende toepassingen van CWA's, (3) het beschrijven van de positieve en negatieve effecten van iedere toepassing, met name wanneer deze gebruikt wordt om informatie te delen, (4) het inventariseren en beschrijven van belemmerende en bevorderende factoren die het gebruik van CWA's beïnvloeden, en (5) het opstellen van een actieplan en stappenplan voor toekomstig onderzoek. Voor deze studie werd gebruik gemaakt van een erkende scoping review-

methodologie, die bestond uit zes stappen: (1) het identificeren van de onderzoeksvraag, (2) het identificeren van relevante studies binnen de geselecteerde databases (met behulp van het programma "Eppi Reviewer"), (3) het selecteren van studies door middel van een iteratief proces waarbij twee onderzoekers de literatuur doorzochten, de zoekopdracht bijstelden en artikelen bestudeerden voor inclusie, (4) het presenteren van de gegevens, (5) het samenvoegen, samenvatten en rapporteren van resultaten en (6) het consulteren van uiteindelijke gebruikers van de resultaten van deze studie ("knowledge users"), tijdens drie bijeenkomsten. Dit laatste is een uniek kenmerk en omvat het samenwerken van drie nationale en internationale "knowledge users": "International Medical Informatics Association", de "Association of Faculties of Medicine of Canada" en de Nederlandse Patiënten Consumenten Federatie (NPCF). De resultaten van dit scoping review zijn beschreven in hoofdstuk zes.

Hoofdstuk 6

In dit hoofdstuk staan de resultaten beschreven van het scoping review dat gepresenteerd werd in hoofdstuk 5. We doorzochten zeven wetenschappelijke databases en zes bronnen voor niet-wetenschappelijke literatuur op artikelen over CWA's, gepubliceerd tussen 1 januari 2001 en september 2011. In totaal werden 6.357 samenvattingen beoordeeld. Alle studies die kwalitatieve of kwantitatieve resultaten presenteerden over het gebruik van CWA's in de zorg werden geïncludeerd in de studie. Dit kwam neer op 111 studies waaronder vier experimentele studies, vijf quasi-experimentele studies, vijf observationele studies, 52 casestudies, 23 onderzoeken met vragenlijsten over het gebruik van CWA's en 22 beschrijvende studies over de kwaliteit van informatie op CWA's. Uit de vragenlijstonderzoeken bleek dat de prevalentie van CWA-gebruik onder studenten en zorgverleners hoog is (> 50%). Ook bleek dat het aantal bijdragen laag is en dat de kwaliteit van de informatie op CWA’s beter zou kunnen. We vonden 57 positieve effecten en 23 negatieve effecten van CWA's, en vonden 48 belemmerende en 91 bevorderende factoren voor het gebruik ervan. De experimentele studies lieten zien dat wanneer CWA's gebruikt worden om kennis en informatie te delen, dit positieve effecten heeft voor fysieke activiteit, controle van de bloeddruk, wetenschappelijk schrijven, communicatie en leiderschap. Er bestaat een groot aantal positieve en negatieve effecten van CWA's als hulpmiddel voor het verspreiden van kennis en informatie in de zorg. Echter, voordat we definitieve uitspraken kunnen doen over de effectiviteit van het gebruik van CWA's, is het belangrijk een systematische review uit te voeren. Hierbij dienen de resultaten van de experimentele en quasi-experimentele studies vergeleken te worden, waarbij rekening gehouden wordt met het risico op publicatiebias. Eveneens moeten nieuwe implementatiestrategieën gevonden worden, waarbij ingespeeld wordt op de vele belemmerende factoren.

Hoofdstuk 7

Hoofdstuk zeven beschrijft de resultaten van een studie, waarin onderzocht werd of wiki's gebruikt kunnen worden om dynamische informatiefolders te maken met participatie van zowel patiënten als zorgverleners. Dit was van belang, aangezien patiënten als ervaringsdeskundigen beschikken over veel kennis, maar ze vrijwel nooit betrokken worden bij het tot stand komen van informatiemateriaal. We hebben een open wiki gemaakt voor Nederlandse patiënten die in aanmerking kwamen voor behandeling in de vorm van intra-uteriene inseminatie (IUI), en een gesloten wiki voor patiënten die in aanmerking kwamen voor in vitro fertilisatie (IVF) en behandeld werden in één academisch ziekenhuis. De haalbaarheid van het gebruik van de wiki's werd bepaald door het analyseren van gebruiksstatistieken en de inhoud van de wiki's. Daarnaast werden ervaringen van gebruikers in kaart gebracht door middel van semigestructureerde interviews. Het bleek dat zowel patiënten als zorgverleners konden werken aan de wiki's, zonder beperkt te worden door tijd en plaats. De open IUI-wiki werd door 2.957 mensen bezocht, en de gesloten IVF-wiki door 424 bezoekers. We vonden 28 barrières voor het gebruik van de wiki's (bijvoorbeeld de ingewikkelde manier van inloggen), en veertien bevorderende factoren (bijvoorbeeld de beschikbaarheid van betrouwbare informatie). We concludeerden dat wiki's veelbelovende hulpmiddelen zijn bij het bevorderen van patiëntenparticipatie met als doel patiënteninformatie te verbeteren. Toekomstige studies dienen actief gebruik verder te stimuleren. Bij het ontwikkelen of kiezen van implementatiestrategieën kan gebruik gemaakt worden van het wijde spectrum aan belemmerende factoren die gevonden werden in deze studie. Daarnaast dienen toekomstige studies gericht te zijn op het evalueren van de kwaliteit van de informatie in wiki's.

Hoofdstuk 8

Dit hoofdstuk beschrijft de resultaten van een observationele studie, waarin onderzocht werd in hoeverre het haalbaar is om patiëntenvragen (vraaggestuurd) te gebruiken om leemtes te identificeren in aangeboden patiënteninformatie (aanbodgestuurd). We redeneerden dat zorgverleners moeten zoeken naar eenvoudige en innovatieve manieren om de door hen aangeboden patiënteninformatie up-to-date te houden, aangezien het bekend is dat goede informatie over ziekte of behandeling cruciaal is: het stelt patiënten in staat om te participeren, betere beslissingen te nemen en het kan bijdragen aan betere zorguitkomsten. Dit is in het met name belangrijk in de fertiliteitszorg, aangezien onderzoek laat zien dat onvolledige en tegenstrijdige informatie door deze patiëntengroep als een probleem wordt ervaren. De haalbaarheid van deze aanpak werd onderzocht door: (1) thema's te identificeren waar patiënten vragen over stelden (onder anderen op een online forum), en (2) door te bepalen in hoeverre de gestelde vragen beantwoord konden worden met informatie uit de door het ziekenhuis aangeboden informatiefolders. Dit stelde ons in staat om eventuele leemtes aan te tonen in de aanbodgestuurde patiënteninformatie. In totaal werden 193 vragen geïncludeerd en werden 24 verschillende thema's geïdentificeerd (bijvoorbeeld bloedverlies tijdens de behandeling, gebruik van medicatie, bijwerkingen). De helft van alle vragen (49,4%) kon niet of slechts gedeeltelijk

worden beantwoord met de bestaande patiëntenfolders. We lieten in deze studie zien dat het haalbaar is om met deze aanpak onderwerpen te vinden waar patiënteninformatie wellicht verbeterd kan worden, wat een eerste stap kan zijn naar het daadwerkelijk verbeteren van aanbodgestuurde informatie door zorgverleners. We lieten in deze studie zien dat zorgverleners zich moeten realiseren dat patiënteninformatie van hoge kwaliteit wensen, maar dat de aanbodgestuurde informatie niet altijd aansluit bij de behoeften van patiënten. Daarom is het belangrijk verder te verkennen op welke manier patiënten beter betrokken kunnen worden bij de totstandkoming van patiënteninformatie. Dit zal nader inzicht geven in de informatiebehoeften van patiënten, en zal zorgverleners helpen om aanbodgestuurde informatie up-to-date en patiëntgericht te houden.

Hoofdstuk 9

In dit hoofdstuk wordt de algemene discussie over de uitgevoerde studies in dit proefschrift beschreven. Allereerst stellen we, gebaseerd op de resultaten van het review beschreven in hoofdstuk 2, een allesomvattende definitie voor *Health 2.0* (In het Nederlands "Zorg 2.0") voor. We beschrijven dat in het '*Health 2.0*-tijdperk' grenzen tussen de verschillende stakeholders (bijvoorbeeld patiënt en zorgverlener) kunnen vervagen. Dit omdat *Health 2.0*-hulpmiddelen patiënten faciliteren beter te kunnen participeren of meer gelijkwaardige partners van zorgverleners te worden. Het blijkt dat *Health 2.0* veel overlap heeft met "e-Health", aangezien beide begrippen te maken hebben met technologie, zorggerelateerde ICT, internet en zorg. Er zijn echter verschillende redenen waarmee *Health 2.0* onderscheiden kan worden van e-Health. Op de eerste plaats beschrijft *Health 2.0* een proces, in tegenstelling tot een momentopname. Ten tweede gaat *Health 2.0* over sociale media en samenwerking met meerdere stakeholders in de zorg, wat het vanzelfsprekend relevant maakt voor alle stakeholders in de zorg. Ten derde kan *Health 2.0* plaatsvinden zonder technologie, in tegenstelling tot e-Health. Gezien deze brede definitie zou *Health 2.0* gezien moeten worden als een overkoepelende term, die verschillende andere begrippen zoals e-Health omvat. We beschrijven dat sociale media de zorg in positieve zin kunnen beïnvloeden, maar dat terughoudendheid belangrijk is omdat er nog weinig wetenschappelijk bewijs wat betreft de effecten is. Daarnaast zijn diverse negatieve of potentieel schadelijke effecten beschreven, zoals een snelle verspreiding van onjuiste of niet-gevalideerde informatie, of problemen ten aanzien van de privacy. Uiteraard dienen deze mogelijke effecten niet uit het oog verloren te worden. We merken op dat, gezien het feit dat een groeiend aantal mensen sociale media en webcams wil gebruiken voor zorggerelateerde zaken, het een gemiste kans is dat de zorg op dit moment nog zo weinig inspeelt op deze wens. Er is nog steeds een leemte tussen wat mogelijk is met sociale media en wat daadwerkelijk wordt gedaan. Daarom adviseren we stakeholders te verkennen of – en op welke manier – zij optimaal baat kunnen hebben bij het gebruik van sociale media. Om de verdere ontwikkeling en implementatie van sociale media te ondersteunen, benoemen we vier belangrijke uitdagingen en mogelijke oplossingen hoe hiermee om te gaan: (1) hoe te onderzoeken of aan te tonen dat sociale media daadwerkelijk effect hebben, (2) hoe om te gaan met de belemmerende factoren in het gebruik

van sociale media, (3) hoe te bereiken dat de zorg meer openstaat voor sociale media en (4) hoe om te gaan met financiële zaken. Tot slot concluderen we dat sociale media veelbelovend zijn, en de zorg in de nabije toekomst verder zullen beïnvloeden, zoals ze dit ook doen in onze gehele maatschappij. Op dit moment zijn de exacte richting, snelheid en impact nog niet duidelijk. Dit proefschrift draagt bij aan het bepalen van de scope en terminologie voor dit nieuwe "Health care Social Media-Tijdperk". Bovendien geeft het inzicht in de haalbaarheid van verschillende hulpmiddelen in de zorg en de bestaande kansen en bedreigingen.

Pagina’s 251 t’m 265 (dankwoord) zijn beschikbaar in hard-copy versie van dit proefschrift.

Curriculum Vitae

Thomas Hendrik (Tom) van de Belt werd geboren in Arnhem op 13 december 1982 en groeide op in de stad Huissen. Na de middelbare school koos hij voor de opleiding fysiotherapie in Nijmegen, wat goed te combineren was met zijn passie marathonschaatsen. Gedurende zijn studie werd een het gevoel dat de wetenschap zijn roeping was verder versterkt. Daarom verkoos hij een studie biomedische wetenschappen aan de Radboud Universiteit. Hij slaagde erin om dit te combineren met het schaatsen van marathonwedstrijden op het hoogste niveau. Tijdens de Master Human Movement Sciences deed hij inspanningsfysiologisch onderzoek bij kinderen met een congenitale hartafwijking, onder leiding van Prof. dr. M. Hopman en Dr. M. Schokking. Daarnaast voerde hij in opdracht van toenmalig minister van Volksgezondheid Welzijn en Sport, Prof. dr. A. Klink, een onderzoek uit naar de responstijden (15-minuten criterium) van ambulances. Na zijn studie kwam hij als junior onderzoeker in dienst bij Acute Zorgregio Oost, en deed onder andere onderzoek met gegevens uit de traumadatabase. Onder leiding van Lucien Engelen was hij betrokken bij de oprichting van het Radboud REshape & Innovation Center, waar hij de kans kreeg zich meer te richten op innovatie in de zorg. In dit boeiende en onontgonnen onderzoeksgebied voelde Tom zich snel thuis en de plannen voor een promotietraject werden gemaakt. In 2010 was het zover, onder begeleiding van promotoren Prof. dr. J.A.M. Kremer en Prof. dr. M. Samsom ging hij aan de slag bij REshape én Verloskunde en Gynaecologie om het gebruik van sociale media in de zorg te onderzoeken. Na het afronden van zijn proefschrift blijft hij bij REshape werken in de functie van Postdoc. Een recent overzicht van zijn publicaties is te vinden via goo.gl/Vgnt6w. Tom is op Twitter actief als @tomvandebelt. Hij woont samen met Cristel en samen hebben zij een zoon.

PhD theses Human Reproduction NCEBP (2000–2014)

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1. 07-02-2000 *Els van der Molen*
   Disturbed homocysteine metabolism endothelial dysfunction and placental vasculopathy
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